

**Title: INVOLUNTARY CHILDLESSNESS: AN
INTERPRETATIVE PHENOMENOLOGICAL
ANALYSIS OF BLACK WOMEN'S EXPERIENCES IN
LUTON**

Name: Ndifreke Charles Atang

This is a digitised version of a dissertation submitted to the University of Bedfordshire.

It is available to view only.

This item is subject to copyright.

**INVOLUNTARY CHILDLESSNESS: AN INTERPRETATIVE
PHENOMENOLOGICAL ANALYSIS OF BLACK WOMEN'S
EXPERIENCES IN LUTON**

N.C. Atang

A thesis submitted to the University of Bedfordshire, in fulfilment of the
requirements for the award of Master of Philosophy (MPhil)

June 2016

**INVOLUNTARY CHILDLESSNESS: AN INTERPRETATIVE
PHENOMENOLOGICAL ANALYSIS OF BLACK WOMEN'S EXPERINCES
IN LUTON**

N. C. ATANG

Abstract

This study aimed to explore the perception and experiences of involuntary childlessness among Black African women in the UK. While there are several studies in the area of infertility, they have usually been focused on national surveys of infertility prevalence and psychological-related stress treatment from a sample selected from White and middle-class women; in addition to a growing literature on the experiences of involuntary childlessness or infertility in developing countries. However, there is a lack of research exploring the impact that ethnicity and culture could have on the perception and experience of infertility within Western societies.

An interpretative phenomenological perspective informed by the philosophical principles of Martin Heidegger (1927–1962) was used to explore the experiences of eight involuntarily childless Black African women in the UK. Semi-structured interviews were used in collecting data, and analysed using Interpretative Phenomenological Analysis (IPA). Three superordinate themes emerged from the data analysis: ‘the vulnerable self’, ‘self and the social world’ and ‘coping with involuntary childlessness’ – revealing the complexities of the women’s experiences. The superordinate themes reflected a common experience shared by the women.

The study revealed a concern about disclosure and exposure of their state of involuntary childlessness and the social judgement and stigma that comes with it; revealing the significant role that the community beliefs and perceptions play in the lives of the involuntarily childless women. The interviews also reveal that the experience of involuntary childlessness or infertility is one that gives rise to emotional pain, grief, loss of self-esteem, isolation and even discrimination.

It is believed that the insights that this study provides will contribute to the empirical studies that have used IPA, as well as provide useful insights for infertility services in Luton as a way of ensuring that services meet the needs of the growing Black and minority ethnic population.

Student Declaration

University of Bedfordshire

Institute for Health Research

MPhil in Public Health

Declaration

I declare that this thesis is my own unaided work. It is being submitted for the degree of Master of Philosophy (MPhil) at the University of Bedfordshire.

It has not been submitted before for any degree or examination in any other University.

Name:

Signature:

Date:

Table of Contents

Abstract.....	ii
Table of Contents.....	iv
Contents.....	iv
List of Tables	vii
List of abbreviations.....	viii
Acknowledgements.....	ix
Chapter One: Introduction.....	1
1.1 Introduction	1
1.2 Justification for the study	2
1.2.1 Research question.....	4
1.3 Structure of the thesis	4
Chapter Two: The infertility care pathway	5
2.1 Introduction	5
2. 2 Prevalence of infertility in the UK	5
2. 3 The infertility care pathway	6
2. 4 Causes, diagnosis and treatment of infertility or involuntary childlessness.....	8
2. 5 Experiences of the infertility services	9
2.6 The Black African community in Luton and local fertility services.....	14
2.7 Summary	15
Chapter Three: Conceptualising involuntary childlessness	16
3.1 Introduction	16
3.2 Definitions of infertility or involuntary childlessness in context	16
3.3 Infertility and its impact on the woman	18
3.3.1 The significance of having children.....	20
3.4 Ethnicity: its impact on involuntary childlessness or infertility	21
3.5 Involuntary childlessness or infertility: perceptions and beliefs	23
3.6 Involuntary childlessness: experiences, coping and seeking solution	27
3.7 Summary	30
Chapter Four: Research Methodology.....	31
4.1 Introduction	31
4.2 Choosing a methodology for inquiry.....	31
4.3 Phenomenology	32

4.4 Reason for using a phenomenological approach.....	34
4.5 Phenomenology as a methodology	35
4.5.1 Relationship between phenomenology and IPA.....	36
4.5.2 Relevance of IPA to this study.....	37
4.5.3 Challenges of using IPA	38
4.6 Research design	39
4.6.1 Debate about suitable sample size for IPA study	39
4.6.5 Rationale for chosen sample size.....	42
4.6.6 Sample frame	43
4.7 Research question.....	43
4.7.1 The sample	44
4.7.2 The topic guide.....	47
4.7.3 Data collection	49
4.7.4 Ethical considerations	50
4.7.5 Process of data analysis	53
4.7. 6 Achieving rigour	54
4.8 Summary	55
Chapter Five: Analysis and Findings	56
5.1 Introduction	56
5.2 The participants' descriptive summary.....	56
5.3 Introduction of themes	59
5.3.1 Superordinate theme one: the vulnerable self.....	60
5.3.3 Coping with involuntary childlessness	81
5.4 Summary	83
Chapter Six: Discussion and conclusion	85
6.1 Introduction	85
6.2 Findings and existing research	85
6.2.1 The vulnerable self	86
6.2.2 Self and the social world	88
6.2.3 Coping with involuntary childlessness	92
6.3 Methodological reflections.....	96
6.4 Study strength and limitations and suggestions for future research	98
6.4.1 Strengths	98
6.4.2 Limitations.....	99

6.5 Contribution to the field	99
6.6 Conclusion.....	100
References.....	101
Appendices	
Appendix 1: Topic guide for the involuntarily childless women.....	128
Appendix 2: Consent Form.....	133
Appendix 3: Demographic questionnaire for the involuntarily childless women	134
Appendix 4: Participant information sheet for the involuntarily childless women.....	135
Appendix 5: Recruitment announcement for involuntarily childless women	138
Appendix 6: Recruitment poster for the involuntarily childless women.....	139
Appendix 7: Recruitment Advert for Online Infertility Forum.....	140
Appendix 8: For Help and Support.....	141
Appendix 9: Ethics approval confirmation letter	142
Appendix 10: Step 4 clustering of themes (IC participant 4)	1
Appendix 11: Example of superordinate themes with quotes	8
Appendix 12: Master table of themes	14
Appendix 13: Infertility care pathway.....	29

List of Tables

Table 5.1	Demographics of involuntarily childless women	57
Table 5.2	Superordinate and sub-themes	60

List of abbreviations

ART	Assisted Reproductive Technology
CCG	Clinical Commissioning Group
DI	Donor Insemination
HFEA	Human Fertilisation and Embryology Authority
IPA	Interpretative Phenomenological Analysis
IUI	Intrauterine Insemination
IVF	In-Vitro Fertilisation
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics
PHC	Primary Health Care
RfO	Race for Opportunity
SRA	Social Research Association
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
WHO	World Health Organisation

Acknowledgements

First and foremost I am grateful to my God for the strength to complete this thesis and for sending such supportive people to guide and direct me throughout this research. I would like to also express my heartfelt appreciation to my husband Charles Atang for his unconditional support and encouragement. I stumbled along, clinging to the thought that if I put my mind to it, I will achieve it, and you gave me the confidence to continue along this journey. Without your all-round support I would not have completed this work. My heartfelt thank you.

To my academic supervisors, Dr Nasreen Ali and Professor Gurch Randhawa: thank you is not even enough to measure up for all the support and encouragement you gave me. I would not be able to complete this work without your invaluable guidance and expertise. I am grateful to you for sharing your constructive criticism, knowledge, insight and timely feedback. I have learned so much from you, thank you.

I would like to thank the participants for giving their time to this study and for their honesty throughout the interviews, without which I would not have had access to such rich data.

To my parents Elder and Mrs Usen Udofia: your prayers and numerous words of encouragement through the telephone helped me during my darkest hours, I say thank you. Finally, thank you to Dr Peter Norrington for proofreading the thesis and offering helpful suggestions.

Chapter One: Introduction

1.1 Introduction

In its recent review of fertility care pathways, the National Institute for Health and Care Excellence (NICE) recognises that infertility can link to psychological problems (NICE, 2015). Infertility can be identified after having regular sexual intercourse for a year without a pregnancy. Infertility has been linked to poor mental health outcomes (Menning, 1982). For example, depression has been linked to adverse maternal health outcomes such as stillbirths, miscarriages, surgery on and removal of reproductive organs, sterilisation, premature menopause and infertility (Patel and Oomman, 1999; Katon and Walker, 1998; Hotopf *et al.*, 1998). Reducing psychological/mental health problems is a key government objective (Department of Health - DoH, 2011) but fertility provision has not been made a priority by the National Health Service (NHS) and is not viewed as a significant health problem since it is not physically ‘visible’ as are other health conditions (RCN, 2009).

The UK has a large and growing ethnically diverse population with evidence showing that the Black African population is the fastest growing group (Mayhew and Waples, 2011). The existing evidence base highlights that ethnicity is an important factor in access and utilisation of healthcare services, and Black and minority ethnic (BME) groups are recorded as having poorer access to healthcare (Nazroo, 2003; Nazroo *et al.*, 2007; Nazroo *et al.*, 2009; Wilson *et al.*, 2012; Szczepura, 2005; Grosios *et al.*, 2010; Greil *et al.*, 2011) due to language problems (Timmins, 2002; Dubard and Gizlice, 2008), lack of effective communication with patients which is crucial to the safety and quality of care (Schyve, 2007), and insensitive services (Culley *et al.*, 2004).

NICE (2013) guidelines recommend that good communication between healthcare professionals and people with fertility problems is vital. Therefore, the type of information, care and support given to them should be culturally appropriate; and should also be made accessible to people who are unable to speak or read English, and they should have access to interpreters and advocates if needed (NICE, 2013b). Moreover, the limited focus on the fertility challenges of the BME groups is representative of racism; for example, the perception that women from BME groups have ‘too many’ babies (Roberts, 1997; Katbamna, 2000; Harris and Wolfe, 2014;

Brown and Chor, 2014; Greil *et al.*, 2011c) and therefore, they seem to have no real issues conceiving pregnancies.

A press release by the Human Fertilisation and Embryology Authority (HFEA, 2006) highlights that hundreds of people from across Britain's minority ethnic communities do encounter some reproductive problems that impact on their ability to have children. The Department of Health (DoH, 2009) urges NHS commissioners to take into account the needs of all differing communities and groups with regards to the provision of fertility services. As the UK is increasingly diverse, it is essential that services respond to that diversity.

There is a significant body of literature based on infertility experiences of different ethnic groups around the world, for example Loke *et al.*, 2012 (Hong Kong), Tabong and Adongo, 2013 (Ghana), Dimka and Dein, 2013 (Nigeria), Inhorn, 1996; 2002 (Egypt), Riessman, 2000 (India), Daniluk, 2001 (Canada). Much of the existing evidence on involuntary childlessness in the developed countries however, focuses on White middle-class women (Greil, 1997; Aseffa, 2011; Kilbride, 2003). There have been some notable studies focusing on the experiences of South Asian women in the UK which have highlighted that culture and religion play an important part in the construction of involuntary childlessness and the way it is experienced by different ethnic groups (Hudson, 2008, 2012; Culley *et al.*, 2004; Culley and Hudson, 2009; Culley *et al.*, 2006; Culley *et al.*, 2007a; Culley *et al.*, 2007b). For example women experiencing involuntary childlessness in highly pronatalist societies feel the most impact (Inhorn, 2003; Hudson, 2012; Hollos *et al.*, 2009; van Rooij *et al.*, 2009). Despite these important contributions, there is a dearth of information on the experience of involuntary childlessness among Black African women in the UK.

1.2 Justification for the study

The evidence base highlights that there is a link between infertility and poor mental health (NICE, 2015). The government recognises that infertility is a real concern and those that have problems conceiving should have access to NHS treatment¹

¹ According to the Department of Health (2009), there have been varying views as to whether priority should be given to infertility services on the NHS. There is no dispute that such debates are only a constructive part of the process of decision making. But some have refuted outright that such services should not be considered on the NHS at all, but such argument is neither rational nor fair.

(Macaluso *et al.*, 2010). HFEA (2006) suggest that there is potentially large numbers of individuals from BME group which tend to be highly pronatalist – who may be affected.

Previous studies carried out in the area of infertility have been focused on national surveys of infertility prevalence, psychological-related stress, and treatment seekers whereby samples have often been taken from the white middle-class groups (Greil, 1997; Aseffa, 2011). Also, although there have been an increased focus on researching inequalities in health between and within ethnic minority communities in the UK (Nazroo, 1997; Johnson, 2006), studies exploring reproductive health seem only to focus on conception and childbirth instead of infertility and reproductive failure (Katbamna, 2000).

There has been a limited focus on the experiences of involuntary childlessness among BME settler communities in the UK (Greil, 1997; Culley *et al.*, 2007; Culley and Hudson, 2009), despite the potentially large number of individuals from BME groups who may be affected (HFEA, 2006) and the evidence that ethnicity impacts on health experience and outcomes (Nazroo, 2003; Nazroo *et al.*, 2007, 2009; Wilson *et al.*, 2012; Szczepura, 2005; Grosios *et al.*, 2010; Greil *et al.*, 2011). Much of the research about infertility in the UK with the exception of research by Culley *et al.* (2009), has failed to explore fully the impact of social context on involuntary childlessness, instead of focusing on the sphere of medical treatment alone. By focussing on involuntary childlessness among the Black African community this study attempts to readdress this imbalance in the existing evidence base.

Population projections for Luton also show that the Black African community is the fastest growing ethnic minority group in the town (Mayhew and Waples, 2011). It is also a highly pronatalist community where motherhood is perceived to be essential to a woman's role (Inhorn, 1996). There is however a dearth of existing evidence on Black African women's experience of involuntary childlessness in the UK and therefore the findings from this study will provide valuable information on how to address the fertility health care needs of one of its largest and growing ethnic groups and thus, contribute to reducing inequalities in health locally.

1.2.1 Research question

What is the experience of involuntary childlessness among Black African women in Luton, UK?

1.3 Structure of the thesis

This thesis is divided into six chapters, including this chapter, which problematise infertility as a recognised health condition which can lead to significant psychological/mental health problems. It also highlights that ethnicity is an important factor in accessing and utilising health care services and BME groups are evidenced as having poorer access to healthcare services.

Chapter two presents the infertility care pathway in the UK and highlights the available evidence on the unequal access to the infertility services as a result of the NHS rationing fertility treatment where access to treatment depends entirely on where one lives in the UK. It also presents the definition and meaning of involuntary childlessness in the context of the study.

Chapter three presents the key conceptualisation of involuntary childlessness and how these have influenced this study.

Chapter four discusses why Interpretative Phenomenological Analysis (IPA) was chosen to be the most suitable methodology to answer the research question and meet the objective. It also presents detail of the study design used.

Chapter five presents the study findings from the in-depth interviews with the involuntarily childless women. Due to the word count limitations the step-by-step IPA analysis is presented in appendices 10, 11, and 12.

Chapter six presents the discussion of the study findings in relation to existing literature. It also outlines the contribution to knowledge, suggestions for further research, reflections and the conclusion of the study.

Chapter Two: The infertility care pathway

2.1 Introduction

This chapter begins by presenting a discussion of the prevalence of infertility in the UK pointing out the difficulty of reviewing prevalence in relation to ethnicity. It then presents the care pathway and associated infertility services in the UK. Drawing on the existing literature it then turns its attention to the experiences of infertile or involuntary childless women and the impact of involuntary childlessness on women's identity. Finally it presents the Luton context and a look at Black African community in the UK and Luton.

2.2 Prevalence of infertility in the UK

A recent estimate based on the NICE guidelines definition of infertility suggests that approximately 1 in 7 couples at some time in their life experience difficulty in achieving a pregnancy (HFEA, 2013). The NICE (2013) guidance attribute 40 per cent of infertility cases to both male and female factors; 25 per cent of cases are classed as unexplained infertility – due to unidentifiable cause, 25 per cent cases are due to ovulatory disorders; 20 per cent as a result of tubal damage; 30 per cent of infertility cases are due to a male factor, and 10 per cent are cases of uterine and peritoneal disorders (NICE, 2013).

Information on the prevalence of infertility by ethnicity at a national level provided by the HFEA (2006) highlights that estimates of people with fertility challenge in Britain based on ethnic classification² are: White British – 2,840,000; White Irish – 42,500; Other White – 95,600; Asians: Indians – 65,800; Pakistani – 40,400; Bangladeshi – 14,600; Other Asians – 15,000; Black: Black African – 29,100; Black Caribbean – 34,600; Other Black – 5,080 (HFEA, 2006). At a local level through hospital records, data may be available but this was beyond the scope of this study.

² Estimates are based on ethnicity classification and data from 2001 Census (HFEA, 2006) as there are no available updated data on infertility prevalence based on the 2011 census. Also, estimates are based on 1 in 7 individuals aged between 18 and 45 years who are unable to achieve pregnancy naturally. There are no available data for Northern Ireland.

2. 3 The infertility care pathway³

In the UK Infertility treatment is provided by the National Health Service (NHS); and NICE guidelines make the recommendation that fertility treatment should be made available on the NHS to women of child bearing age and their partners who have not been able to conceive a pregnancy over a period of twelve months without any known origin of their infertility (HFEA, 2013). The guidelines further recommend that an earlier referral should be made if the woman is 36 years and above (HFEA, 2013). Women who are 39 years and under are recommended to be offered three full cycles of IVF treatment if they have tried to conceive without success for a total of two years; and women aged 40–42 years should be provided with one cycle of treatment on the NHS (NICE, 2013).

However, due to the so-called ‘⁴postcode lottery’ of IVF, the treatment of infertility varies significantly from zero to three cycles of treatment in most Clinical Commissioning Groups (CCGs) in England. In 2013, NICE recommended that the NHS should no longer use the postcode lottery system as way of funding fertility treatment because it only encourages inequality in health. For example, less than one in five CCGs in England make available the recommended three cycles of IVF treatments, whilst over half of the CCG only fund one full cycle of the treatment to couples who are eligible. Some places in the northeast of England like the Vale of York do not fund the IVF treatment at all (NICE, 2014).

Since the first publication of its fertility clinical guidelines in 2004 and a subsequent iteration in 2013, NICE guidelines have recommended an approach (in other words – care pathway) to healthcare professionals on how to best manage individuals with reproductive failure. The care starts when a woman of childbearing age who failed to conceive a pregnancy after a period of about twelve months of regular unprotected sexual intercourse in the absence of any known cause of such failure, go to their

³ A care pathway, according to Vanhaecht *et al.* (2010), can act as a fully integrated information system for healthcare professionals to map out landscapes of care, which offers forms of direction or framework for decision-making and for organisation, managing and documenting care of patients. See Appendix 15 for a comprehensive flow chart illustration of the infertility care pathway as recommended by NICE (2013).

⁴ IVF treatment postcode lottery here means that the situation of NHS-funded treatment in England varies according to one’s postcode.

General Practitioner (GP) as their first point of medical contact; the GP then offers basic clinical assessments and investigation of the woman along with her partner. If the couple have been actively trying for a total of at least two years and there is no obvious cause for their inability to conceive, the couples are then referred to a specialist care. The referral is however made earlier if the woman is 36 years old and over or where there is an already established cause for the infertility. Once the referral is received from the GP, it is reviewed by a consultant in reproductive medicine who can either confirm if the referral is appropriate, redirect the referral to the appropriate clinic (for example endocrinology), or contact the GP if it falls outside the agreed referral criteria. Given the number of causes of fertility problems (see section 2.5), the provision of proper investigation is vital, hence, the infertility care pathway.

The necessary investigations given at secondary care include: assessment of ovulation, tubal damage and uterine abnormalities, semen analysis, as well as screening for infections such as chlamydia trachomatis and susceptibility to rubella (NICE, 2013b). On establishment of diagnosis, treatment falls into three categories:

- 1) Medical treatment (e.g. the administration of ovulation induction medications)
- 2) Surgical treatment (such as laparoscopy for ablation of endometriosis, hysteroscopy for removal of uterine polyps, open-incision for removal of fibroids, etc.)
- 3) Assisted reproductive techniques (e.g. mostly involves handling of gametes or embryos).

There are no local or national data available to show ethnic monitoring and patterning with regards to the use of infertility services in the UK (Culley *et al.*, 2004). Available data are those provided by the HFEA to show clinics that perform in vitro fertilisation (IVF) and donor insemination (DI) and the number of women having this treatment by region. The data shows that 78 licenced clinics performed IVF treatment and 75 clinics performed DI treatments and a third of these clinics are located in London (HFEA, 2013). The number of women treated in each region ranges from 1,322 in Wales to 15,469 in London (HFEA, 2013). Bedfordshire which

is regionally located in the East of England, has six licenced fertility clinics performing IVF and DI with a total number of 2,771 women treated in 2013 (HFEA, 2013). This figure includes both NHS and self-funded patients.

2. 4 Causes, diagnosis and treatment of infertility or involuntary childlessness

A detailed discussion of a definition of infertility and involuntary childlessness is presented in Chapter three, section 3.2. Within the developing countries, unsafe abortions, post-partum pelvic infections, genital mutilation, childhood marriage which increases the risk of developing vesicovaginal fistula and tubal problem secondary to sexually transmitted infections/diseases (STIs/STDs) and severe pelvic inflammatory disease (PID), are said to be the main contributors of female infertility (Fadare and Adeniyi, 2015). Chlamydial trachomatis, mycoplasma infection, gonorrhoea and tuberculosis are some common STDs that have been indicated to be the cause of blocked fallopian tubes (tubal occlusion) in most female infertility in Africa (Osazuwa *et al.*, 2013). Such resultant causes may be because infertility is strongly associated with social, behavioural and cultural factors that expose women to the risk of infertility due to STIs and other reproductive tract infections (Aseffa, 2011). Similarly, male-factor infertility has been known to occur as a result of reproductive tract infections which may be associated with poor semen count and morphology (Abarikwu, 2013).

Treatment for infertility may begin when a woman fails to conceive despite regular sexual intercourse and she decides to seek medical intervention. Within twelve months of regular unprotected sexual intercourse, 84% of women of reproductive age are estimated to conceive a pregnancy, 92% will conceive following a period of 24 months and an estimated 93% will conceive after an accumulated 36 months period (NICE, 2013). In the UK, the process of investigation and treatment of infertility starts when couples report their inability to conceive to their local GP, which follows a period of testing of both partners, which may or may not result in a medical diagnosis of the cause of their inability to get pregnant. Results from the diagnosis will then determine the treatment that will be administered to the couples. In the UK, there are a number of fertility treatments available ranging from the least intrusive to the most advanced reproductive treatment options including; ovulation induction (OI), intra-uterine insemination (IUI), gamete intra fallopian transfer

(GIFT), in vitro fertilisation (IVF) and intracytoplasmic sperm injection (ICSI), invitro maturation (IVM), embryo testing amongst others (HFEA, 2014). Moreover, as of 2014 according to the HFEA trends and figures, the most common fertility treatment was either IVF or ICSI with statistics showing over 52,000 women receiving it and majority of these treatments – 6 in 10 – were privately funded (HFEA, 2014).

However, these large numbers belie the relatively unsuccessful nature of assisted reproductive technologies (ARTs). For example, in 2011 out of 28,979 fresh embryos that were transferred to infertile women during their IVF treatment, less than half (14,020) resulted in a successful pregnancy and childbirth (HFEA, 2012). These successes recorded, however, vary with some individual clinics achieving a higher rate of success. The period of time that a couple will continue with fertility treatment is highly variable, and can be determined by a number of factors including whether or not they become pregnant; their financial resources; their willingness and ability to continue; as well as the willingness of their clinician to continue to treat them (Peddie *et al.*, 2005). Since the success rates of ARTs are relatively low, the experience of infertility treatment is overwhelmingly one of failure and disappointment (Throsby, 2004).

2. 5 Experiences of the infertility services

Although there are no local or national data on the use of infertility services by different ethnic groups, the literature on BME groups' experiences of infertility services highlights that BME women's experiences of infertility services are poor. For example, Hudson (2008) highlights in her study among British South Asian women who had fertility problems that almost half of them had concerns about the level of service that they had received. The author posits that participants raised the issue of poor services, even from known and reputable clinics, citing insensitivity from staff, and difficulty in communicating with the clinic. There were also issues of unsatisfactory explanation of the reason for continuous failed IVF treatments as narrated by one of the participants; while another participant even cited her ethnic background as the cause of her unsatisfactory treatment experience (Hudson, 2008).

A great deal has been written about the impact of involuntary childlessness on women's lives and focuses in particular on: mental health and psychological issues, self-image and identity, self and community stigma, and loss of primary goal.

As already mentioned, one of the government's key objectives is to reduce psychological/mental health problems; where infertility is recognised as a medical condition which can impact negatively on the lives of those affected such as leading to severe distress and depression, the so-called postcode lottery IVF treatment only increases the impact of the problem as it causes widespread inequality.

For many couples, pregnancy will occur when planned, but infertility is a reality for up to 15 per cent of reproductive-age couples (Johansson *et al.*, 2010). The increased rate of failure to conceive pregnancy and bear children is frequently considered a personal tragedy and a curse for the couple and the entire family. In many cultures around the world and especially among the Black Africans, womanhood is defined through motherhood and women who are unable to achieve pregnancy are blamed for the couple's inability to bear children (Dhont *et al.*, 2011). Also, where there is limited or no social security system in place, older people are mostly usually dependent on their children. Therefore, those without children are frequently marginalised, stigmatised, isolated and neglected (Cousineau and Domar, 2007; Akinloye and Truter, 2011). Infertility is considered a crisis but the excessive pressure exerted by a traditional societal structure such as those in Africa and Asia increases the seriousness of the problem (Bolsoy *et al.*, 2010; Pottinger *et al.*, 2006).

Involuntary childlessness can impact on the identity and self-image of women from highly pro-natalist societies (Holloos, 2003; Hudson, 2008; 2012; Culley and Hudson, 2009) and the significance of fertility and motherhood to the female role cannot be overemphasised in such societies. Sundby and Jacobus (2001) argue that in certain parts of southern Africa, giving birth to a child gives a woman the right to share in her husband's property and wealth. For example, in Vietnam, Pashigian (2002) posits that womanhood and motherhood are undifferentiated; affirming that a couple who attempts to bear a child is only conforming to society's norms about parenthood. Among the Yorubas in Nigeria according to Pearce (1999), certain roles engaged by an adult woman depends on her status as a mother because there is a strong belief that children are important for the continuation of family lineage.

Even though many societies expect that adults should have children, the degree of such expectations and its impact on those who are unable to achieve that parenthood status significantly differ across diverse cultures. Authors who have explored the different cultural experiences of involuntary childlessness in less developed countries have revealed the often shattering consequences for the overall wellbeing of involuntarily childless women (Inhorn and van Balen, 2002; Fledderjohann, 2012). For example, Culley *et al.* (2006) who explored infertility experiences and perceptions among the British South Asian communities in the UK contend that members of these communities uphold a strong pronatalist belief system where marriage is very important and childlessness is highly stigmatised. Several authors have reported that witchcraft or evil spirits, punishment from the gods as a result of sins committed in the past, wrath of God, continuous use of birth control measures are all common beliefs strongly held by many societies in Africa to be the cause of involuntary childlessness (Pottinger *et al.*, 2006; Donkor, 2008; Obono, 2004; Makoba, 2005).

The existing evidence base recognises that infertility can link to psychological problems (NICE, 2015). The extent of the psychological impact of a couple's experience with infertility, in addition to an increasing number of affected couples, has created a public health concern (McCarthy, 2008; Peters *et al.*, 2011). Peters *et al.* (2011) have also reported that involuntary childless couples experience less psychological well-being and more grief. Grief related to involuntary childlessness has been found to be on-going and therefore with a potential to be labelled as a maladapted psychological state. Moreover, with the secrecy and misunderstanding surrounding involuntary childlessness, it is more difficult for people to understand and appreciate the loss and grief of these couples, a reason why such grief is not widely explored. Contrary to the death of a family member or friend which is quite often shared with many others, infertility-related grief is not typically a public affair.

Involuntarily childless women have compared their emotional pain to a continual cycle of hope, despair, and disappointment and then become hopeful again, with each and every menstrual period (Bell, 2013). Similarly, Greil *et al.* (2011) compiled a list of themes from their interviews with infertile women who described their intense feeling of complicated grief and loss to include, negative identity or self-image; feeling worthless and inadequate; lack of personal control (especially over

the things they had to go through such as ARTs); become angry and resentful; suffer depression, anxiety and stress; experience lack of satisfaction in life; feel isolated; become jealous of other pregnant women and mothers with children, lose their dream of procreating; and feeling like an ‘emotional roller coaster’.

Gold (2013) describes infertility as a ‘common life non-event’, where non-event can be seen as a normal life transition that fails to happen within a given time frame. Sometimes, this anticipated transition may eventually occur; however, there will be a shift in time frame of that transition which may result in such individuals to be out of ‘sync’ with age mate with regards to the anticipated and realised time frame. While the predicament of involuntary childlessness is known to affect almost every part of the affected couple’s lives as their desire and natural expectation of having children and settling down into an family life is uncontrollably hindered, it is also recognised that the couple’s involuntary childlessness do affect their immediate families (Gold, 2013).

Initially, the couple would have thought that their inability to conceive a pregnancy was due to not having sexual intercourse at the right time (fertile window) and thus carried on living in denial, but as each month continues to pass by without success, they become shocked and disheartened. From the shock of their inability to conceive, the family suffers from long-term chronic stress (Gold 2013). Several studies have evident the association of infertility with significant levels of stress, depression and anxiety amongst involuntarily childless women in Africa, where the normative expectation of childbearing is respected and valued (Upkong and Orji, 2006; Naab *et al.*, 2013; Barden-O’Fallon, 2005; Dyer *et al.*, 2005; de Kok, 2009; de Kok and Widdicombe, 2008; Donkor and Sandall, 2007).

Furthermore, involuntarily childlessness may pose a threat to a person’s important life accomplishment. Gold (2013) argues that this phenomenon is classed as serious as the death of a loved one. In most cases, once diagnosed with infertility, the emotional responses could be quite overwhelming. The involuntarily childless couples are beset by all forms of emotions including; blame, guilt, envy of other pregnant women, disbelief, becoming distressed, denial, frustration, sadness, depression, jealousy, feeling powerless, scared of advancing age, sorrow, regret,

helplessness, self-accusation over their past behaviours, and feeling like a failure in life (Gold, 2013; Loke *et al.*, 2012; Harris and Daniluk, 2010).

Existing literature suggests that the burden of non-conception rest disproportionately on the woman's shoulders. Apart from the stereotype that infertility is a 'woman's problem', it has been reported that men do easily place the blame of the couple's childlessness on the female partner, partly because of men's reluctance to pursue infertility testing (Omoaregba *et al.*, 2011; Fledderjohann, 2012) and the ease of bruising their ego. This is because it has been assumed that women easily bear the blame of the couple's involuntary childlessness in the relationship since the physical manifestation of pregnancy is an obvious sign of fertility, as those without the physical sign of pregnancy risk confrontations and social stigma (Fledderjohann, 2012).

Helen Pilcher (2006) a science writer from Nottinghamshire published a report in the Nature journal about an involuntarily childless Zimbabwean woman Betty Chishava who was thrown out of her family home because of her inability to conceive a pregnancy and her refusal to engage in sexual intercourse with her brother in-law in order to increase her chances of conception. This is because infertility is seen as a taboo in many Black African societies and narratives like that of Betty is quite common in these societies.

These social discrimination and stigma are not just recent events but they have been recorded since the early 80s. For instance, Pfeffer and Woollett (1983) argued that involuntary childlessness is perceived both as a taboo and stigma which seems to wipe away all other 'identifying markers' in the life of individuals suffering from it. Moreover, there are reports that spending time with other pregnant friends and family members or even other children, are activities that involuntarily childless women avoid to be involved in. Some are reported to avoid family events and functions that may make them encounter that which will remind them of their childlessness (Lampman and Dowling-Guyer, 1995; Rapport, 2003).

Miall (1986) highlighted that such avoidance stems from involuntarily childless women believing that revealing their reproductive challenge to others will make people stigmatise them. Thus, even though social support like communicating with others has been found helpful, friendships and association with others are ruined due

to involuntary childlessness (Lampman and Dowlin-Guyer, 1995) because such relationships have also been reported by involuntarily childless women of receiving unsolicited advice to take things easy and not to worry, to on holidays and stop working too hard, or even resign altogether from their jobs. There are also reports of some women to go down the child adoption route as a solution to their infertility (Harris and Daniluk, 2010; Lampman and Dowling-Guyer, 1995).

The social stigma linked to involuntary childlessness is felt most strongly in pronatalist societies. Black African communities (like South Asian communities) are seen to be particularly pronatalist. The next section presents information on the Black African settler community in Luton which was selected as the focus of this study.

2.6 The Black African community in Luton and local fertility services

Luton (situated in the South East of England) has a population of approximately 202,748 (ONS, 2011). Local projections highlight that the Black African ethnic group has grown from 11,700 to 19,800 (as compared to South Asian population which has grown from 33,600 to 50,000 by 2010; meanwhile, the White and Other population has fallen from 139,000 to 132,000 (Mayhew and Waples, 2011).

Earlier study by Oliver and Shapiro (1995) highlighted a few things about the Black Africans who live in the UK. The authors mentioned that Black Africans do not cope well socio-economically. For instance, they indicated that Black Africans who reside in the UK do not occupy the kind of job (e.g. professional and management) positions that would reflect their academic qualification because of a number of factors including language barrier, academic qualifications that were obtained in non-UK institutions, and racism (Oliver and Shapiro, 1995). They also posit that even with their high levels of education and qualifications, Black African men were second to the Black Caribbean men in terms of their level of unemployment, and Black women's unemployment level is only exceeded by their Pakistani counterparts (Oliver and Shapiro, 1995).

Infertility services in Luton are provided by the Luton and Dunstable (L&D) NHS Trust who commissions services by the East and North Hertfordshire Clinical Commissioning Groups (CCGs) on behalf of the eighteen CCGs within the East of

England, to provide specialist fertility treatment for couples who meet the eligibility criteria. The clinical management of eligible couples is in line with the national fertility care pathway (discussed above in Section 2.2) based on the NICE (2013) clinical practice algorithms but modified by individual CCG policies. The infertility care pathway used by the L&D NHS Trust mirrors that of the national infertility care pathways provided by NICE guidance by identifying the tests and treatments to be undertaken within Primary care (Level 1), Secondary care (Level 2) and Tertiary care (Level 3). Level 1 care is provided by the GP when couple present themselves with a fertility problem. Level 2 care commences when the couple is referred to the consultant-led fertility clinic by the GP; and level 3 care commences on referral of the couple to a centre for assisted conception by the consultant from the secondary care.

Luton which has a large Black African population some of who will have used the fertility services, made Luton a relevant research site for understanding Black women's experience of involuntary childlessness.

2.7 Summary

This chapter presented a discussion of the prevalence of infertility in the UK and highlighted prevalence of infertility by ethnicity. It presented the current infertility care pathway and associated services. The discussion then turned to the experiences of BME groups and experiences of infertility services highlighting the impact involuntary childlessness has on the identity of women from highly pro-natalist communities such as the Black Africans. Finally it presented a look at Black African community in Luton where this study was based.

Chapter Three: Conceptualising involuntary childlessness

3.1 Introduction

This chapter turns its attention to a critical discussion of the definitions of involuntary childlessness and infertility, and in doing so, presents the key established conceptualisations of involuntary childlessness and how these have influenced this study.

3.2 Definitions of infertility or involuntary childlessness in context

Infertility has been variously defined in the literature. The World Health Organization (WHO) and the International Committee for Monitoring Assisted Reproductive Technologies (ICMART) release an international glossary of Assisted Reproductive Technology (ART) terminology which defines infertility as “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (Zegers-Hochschild *et al.*, 2009). In general, and for the purpose of this study, infertility is defined by the NICE guidelines (2004) as “failure to conceive after regular unprotected sexual intercourse for one year in the absence of known reproductive pathology” (NICE, 2014).

Infertility is not only limited to the failure to conceive pregnancy within a given period of time, but also the inability to conceive a second or even third pregnancy. The definition of infertility is divided into two categories; the primary infertility and secondary infertility. Primary infertility occurs when a woman fails to conceive a pregnancy within a certain period time frame due to a number of factors including spontaneous abortion, still birth and any other complications that could prevent viable pregnancy and successful birth; while secondary infertility occurs when a woman who had previously conceived a pregnancy fails to conceive a subsequent pregnancy after a given period of time of engaging in unprotected sexual intercourse due to various reasons including infection, scarring of the womb and many more (Oakley, 2011).

Secondary infertility occurs more commonly than primary infertility, especially in developing countries where sexually transmitted infections are common. In many countries, induced abortion contributes a great deal towards secondary infertility. It accounts for 60 per cent of the total number of infertility cases (Zegers-Hochschild *et al.*, 2009). In all these conceptualisations of infertility, the United Nations define

health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 2004) in all issues that relates to its functions and processes. Therefore, infertility accordingly is a source of reduced mental health and social well-being.

The term *involuntary childlessness* is preferred to the term *infertility*, particularly with regards to assisted reproductive (ART) services. Reason being that there are some women who utilise ART but are not infertile rather, they have spouses who are infertile due to medical conditions; some are grouped under ‘unexplained infertility’ because there are no medical reason for their infertility; and there are those group of women – like the nuns – who are bound by their religious belief not to engage in normative formation, which means conventional conception is not very likely for them. (Bell, 2013). Therefore, the term involuntary childlessness more accurately captures this array of circumstances. For the purpose of this study, the term *infertility* will be used to describe those who have been clinically diagnosed with fertility problems (NICE, 2004). Although the term *involuntary childlessness* is also commonly used as a ‘loose’ synonym for infertility, it will be used here to include: those who have not had a clinical diagnosis of infertility, those unable to conceive pregnancy, and those who have experienced pregnancy loss (miscarriages), stillbirth and infant/child loss (Ibisomi and Mudege, 2013).

Ideas about involuntary childlessness are also context specific. For instance in Western societies, after the feminist revolution that occurred in the 60s and 70s, motherhood have been seen as an important element of a woman’s life and as such, a good number of women and their partners choosed to be voluntarily childless (Ginsburg and Rapp, 1995). Thus, childlessness in the Western context can sometimes be chosen as a lifestyle option. Meaning, childlessness can be *voluntary* as opposed to *involuntary* and, in either case; it is something perceived as deeply personal. Thus, when a Western couple is without children, it is difficult for others to know if this is voluntary or involuntary and this blurring tends to obscure the visibility and importance of the later (Inhorn and van-Balen, 2002).

However, in many developing societies where pronatalism is highly valued and parenthood is mandatory, those without children suffer the consequences of childlessness. Limited research by the Western scholars on infertility within

developing countries - including in some cases, their desire for the high-tech assisted reproductive treatment, reflects the massive discourse of Western population policy makers who are keen about reducing the ‘hyper-fertility’ of non-Westerners and thus, do not think that those in such places require such expensive high technology infertility treatment (Greil *et al.*, 2011). In other words, helping infertile subpopulations in high fertility non-Western settings – where infertile individuals may suffer more because of their “barrenness amid plenty” – has never been treated as a high priority in international population discourse and may even be viewed as contrary to the Western interest in global population control (Greenhalgh, 1995; Lane, 1994).

As earlier mentioned, because of a number of reasons – including intrusive and in some cases life-threatening medical interventions, social stigma and community ostracism, marital instability, fear, pressure, and issues around self-image – women worldwide are seen to carry the major burden of involuntary childlessness (Greil *et al.*, 2011). However, all these social and psychological consequences of the failure to conceive and bear children seem to be more significant for women from the developing countries than for women in Western societies (Inhorn, 1994; Kielmann, 1998; Sundby, 1997).

3.3 Infertility and its impact on the woman

The wider literature in the area of infertility and involuntary childlessness that have assessed gender differences have highlighted that the negative impact of infertility is felt more by women than men. Given that the impact of involuntary childlessness is significantly experienced by women from pronatalist societies, this provides the rationale for this study choosing to explore the experiences only of women. Firstly, Black African societies are pronatalist in nature and motherhood under patriarchy is compulsory (Roberts, 1993); where patriarchy is a social system characterised by relations of power and authority of men over women (Inhorn, 1996).

Such societies are prominent in exerting structural and ideological pressures on women to become mothers because motherhood is a woman’s major role and respected female identity (Donkor and Sandall, 2007). Roberts (1993) further suggests that in such patriarchal societies, no woman achieves her full position as a woman until she gives birth to a child. Similarly, Miall (1994) highlights that the

motherhood mandate in a dominant African culture is so strong that it is often assumed any woman who does not have children, regardless of the reason, is a deviant.

Moreover, as infertility is known to occur in both men and women, women are often blamed for the fertility challenge of the couple regardless of the medical cause. They are reported to carry a greater part of the social burden of their reproductive failure which often leads to accusation, divorce or broken relationships, isolation, stigma, and economic insecurity as a result of marital instability (Greil *et al.*, 2011; Hampshire *et al.*, 2012; Leke *et al.*, 1993; Sundby, 1997; Dyer *et al.*, 2002; Rapport, 2003).

In addition, involuntarily childless women see their childless situation as shameful because it makes them feel like a failure. Therefore, to not feel as a complete failure, most of these women strive to stay away from social gatherings or functions – such as baby showers, baby naming ceremonies, children's birthdays and other events/ceremonies – that bring friends and families together just to avoid revealing their involuntary childless status (Rapport, 2003).

It is assumed that involuntary childlessness is an experience that profoundly affects the sense of self and alters, in fundamental ways, the lives of those whom it affects. It is also believed that the ever-widening range of medical reproductive technologies and options available to couples to pursue their 'baby-dream' makes it even more difficult for some to renounce parenthood. There are assumptions that infertility is always the fault of the female partner in a relation because of age old beliefs that has been held about some fertility goddesses who has the power to control life and death (Powel, 2001). In brief, compared to men, women are prone to have lower self-esteem, suffer depression, experience lower life satisfaction, will always blame themselves for infertility, avoid pregnant women and children, are more proactive in seeking out information about infertility, and even initiate treatment (Harris and Daniluk, 2010; Wright *et al.*, 1991; Beaurepaire *et al.*, 1994; Pasch, 1994; Berg *et al.*, 1991; Abbey *et al.*, 1991; Ulbrich *et al.*, 1990; Becker and Nachtigall, 1994)

One of the most remarkable features about the desire for a family is the widespread acceptance of its desirability – whatever the reason, and the associated attractions of parenthood. These particular orientations have frequently been described as

pronatalism. Peck and Senderwitz (1974) describe pronatalism as “any attitude or policy that is ‘pro-birth’; that encourages reproduction and that exalts the role of parenthood”. Most societies are, and have been pronatalist. Indeed, some have argued that pronatalism has become so deeply embedded in the social structure of society and the personalities of its individual members that having children has become a ‘moral imperative’ (Owen, 1986).

Though a great number of societies around the world are pronatalist in nature, some lay specific emphasises on the importance of motherhood to a woman’s identity as experiences of infertility is significantly influenced by patriarchy. For example, Inhorn (2002) highlights that some Egyptian women are known to blame themselves for infertility even if they know that the problem is from their male partner. Similarly, in the Bangladeshi slum areas Papreen *et al.* (2000) report that men are advice to marry another wife because they believe that women are the cause of the couple’s childlessness. Jenkins (2002) also points out about a woman in Costa Rica who accepted to remain childless because of her husband’s refusal to have fertility investigation for their failure to get pregnant.

Logically, the propensity for a couple to blame themselves for their reproductive failure is only a natural way of trying to come to terms with their already troubled situation, a system of belief encouraged by society’s norms regarding the importance of family lineage/continuation (Gonzalez, 2000). Possibly one of the most difficult emotional response to impact of infertility is losing control over one’s life (Domar and Seibel, 1997) especially for women whose bodies are central to almost all parts of the couple’s fertility investigations, diagnosis and the subsequent treatment that follows; such that it becomes the prime focus of her daily living to the point of excluding other equally essential aspects of her life that they now become secondary to the involuntarily childless couple’s life goals. For example, the processes surrounding ART may result in barriers to women’s daily jobs or even career such as juggling through series of hospital appointments and catching up with work.

3.3.1 The significance of having children

Studying involuntarily childless individuals promote understanding of the issues of childlessness such as: why people want children, nature and influences of the decisions they make about having them and some consequences of not having

children for those that want them. A possible answer to why people want children may be that having children is instinctive and such instincts are attributed to women. The alleged importance of the 'maternal instinct' appears in much classical psychological theory, which asserts that the achievement of motherhood is essential to women's well-being; and according to infertility specialist Newill (1974), for the vast majority of individuals it is a primary impulse to find a mate and rear a family of children.

Some scholars have even attempted to explore variety in norms and beliefs about children within and between societies. Based on a social psychological model developed by Hoffman and Hoffman (1973), they analysed some items applied cross-culturally to produce some general *beliefs* about having children. Hoffman and Hoffman posit that children are believed to provide emotional benefits (happiness, companionship, love); economic benefits which are seen from children's help in the house like running errands, care for younger siblings, physical care, old-age security for the parents; self-enrichment/development such as having a sense of fulfilment and feeling of competence as a parent; identification and pride in seeing the children grow; and the importance of continuity and fulfilment of marriage.

Ethnic groups place varying degrees of emphasis on family and children. For example, Chinese Americans believe that their spousal relationship is secondary to the parent-child relationship. In fact, Confucius, the ancient Chinese philosopher, believed that family constituted the most important institution in society (Cooper-Hilbert, 1998). It can equally be observed that in some societies, many women opt to settle down to family life early in their lives to have children, like some young African-Americans who chose rather to have children out of wedlock than risk childlessness (McGoldrick Preto *et al.*, 1991).

3.4 Ethnicity: its impact on involuntary childlessness or infertility

Ethnicity can be understood as the shared origins or social backgrounds and traditions that leads to as sense of unique identity, which is passed down from one generation to another (Senior and Bhopal, 1994). People in the same ethnic group identify with one another based on common ancestry, language, cultural or national experiences. Ethnicity can be regarded as an inherited status.

With regards to those challenged with reproductive health, Tarun (2006) investigated the socio-demographic differences between patients with fertility problems based on their race and ethnicity and found that African-American women are known to experience prolonged periods reproductive failure before they go on to seek for medical attention compared to Caucasian women. Tabong and Adongo (2013) also evaluated the association between ethnicity and involuntary childlessness as well as the supposed reasons for inability to conceive a pregnancy and concluded that there is a strong relationship between ethnicity and involuntary childlessness and the perceived aetiology of infertility.

It can be argued here that how couples evaluate their reproductive challenge is based on their beliefs about parenthood, and such beliefs are influenced by their sociocultural environment. This means that, how a person appraises their reproductive failure will determine their response to it, which will consequently influence their level of anguish; as Cooper-Hilbert (1998) suggests, a Black African married to a Caucasian Canadian may experience infertility quite differently from his spouse. The impact of involuntary childlessness on individuals may vary considerably depending on certain factors such as; gender, race, class, religion, age, sexual orientation, and rural-urban location (Mohanty *et al.*, 1991; Cooper-Hilbert, 1998). In other words, women from different societies and cultural background with fertility issues are strongly influenced by their socio-cultural environment.

In a recent study about endometriosis in the UK among women from different ethnic groups, Denny *et al.* (2011) highlight from their focus group discussions which involved participants from five different ethnic groups in the UK – Indian, Pakistani, African-Caribbean, Chinese and Greek/Greek Cypriot – that in communities where achieving the status of motherhood is an expectation from every adult woman, childlessness be it voluntary or involuntary, is highly stigmatised because women without children feel pressurised by their families and this consequently affect their feelings of self worth. The authors also indicate from their findings that members from all the five groups report that involuntarily childless women are often blame for the lack of children within a marriage or long term relationship (Denny *et al.*, 2011).

3.5 Involuntary childlessness or infertility: perceptions and beliefs

According to Vision (2009), beliefs are informed by perception, and Roesster (2009) argues that common sense “epistemology regards perceptual experience as a distinctive source of knowledge of the world around; which is often interpreted in terms of the idea that perceptual experience, through its representational content, provides us with justifying reasons for beliefs about the world around us” (Roesster, 2009). People view beliefs as just the way they *hold* the world (or certain parts of the world) to be; which suggests that what people think about the world may not be an absolute truth. Thus, there is a difference between what people believe the world is, and what the world truly is. Philosophers have argued that a better way to find out what people truly believe is to carefully observe how they behave or deal with things around them. This is because people will always react according to what they believe rather than what they *say* they believe.

Erroneous belief or misconception is a source of misleading information which may influence one’s attitude towards the uptake of reproductive health care. Fulford *et al.* (2013) contend that the Health Belief Model suggest it is important to take into consideration what people already know about fertility or infertility so as to have an understanding of why they fail to take-up necessary measures that will help increase their chances of conception. There are people with limited knowledge about infertility and its causes which may consequently impact on their treatment seeking behaviour especially among involuntarily childless people. For instance, Bunting and Boivin (2008) highlight in their study of infertility myths and misconception that over half of their questions on fertility facts, risks and myths were only correctly answered by an average number of their study participants; while even less than an average of the participants could correctly identify age as a major risk factor for female infertility.

This means that with an adequate understanding of their reproductive health and factors that may lead to infertility, people could help to guide against reproductive problems in the first place. For example, by creating effective awareness and giving adequate information/educating people about the various STDs and STIs and those that are treatable, could result in reduced prevalence of infertility. There are certain myths and misconceptions surrounding infertility in many societies around the

world. Daniluk (2001) report about the kind of misconception or in this case, beliefs that the Tanzanians hold about infertility. The author maintains that Tanzanians strongly believe evil forces to be the cause of infertility and thus, they engage in unhealthy practices and gross traditional remedies to resolve their fertility problem; from standing on one's head after sexual intercourse, to eating one's fecal matter to bring on vomiting (Daniluk, 2001). It can be argued that people from such socio-cultural environments are influenced by the perception that such practices can only help them remedy their childlessness because they believe it to be *true*.

Sir Peter Strawson, one of the most distinguished philosophers of the 21st century always emphasised in his philosophical writings that the concept of knowledge and perception are closely related and opines that a more fundamental way to understand such connection is that knowledge should easily be traced to its main source (Strawson, 2008). This suggests that, people can claim to *know* things only if they understand how such things came to be, or can be linked to the original source. Strawson (2008) argues that knowledge can originate from different sources but an absolute basic source of knowledge is perception.

Perception can be defined in more than one way. Scientists define perception as our recognition and interpretation of sensory information which includes *how* we respond to information (Daniel, 2011). However, for the purpose of this study according to social scientists and anthropologists, perception can also be a *belief* or *opinion*, conceived by a number of individuals based on how things seem; and the way things are regarded, understood or interpreted. William (2016) posits that perception "is the process by which people translate sensory impressions into a coherent and unified view of the world around them; though necessarily based on incomplete and unverified or unreliable information, perception is more often equated with reality in practice".

Since there are no specific theories with regards to the impact of infertility on the lives of those challenged by it (Stanton and Dunkel-Schetter, 1991), it is debateable that there are several possible reasons why different people react and respond to involuntary childlessness. For instance, the inability to bear children or even bearing the 'wrong' gender of a child (especially female), holds diverse meanings to people from different societies and cultures.

The Korean and Taiwanese hold a strong belief of the significance of having a male child who will be able to carry-on with the family ancestral rituals in order to ensure the family continuity. This means that the absence of a male child in such families place an equivalent impact on them just like those who are involuntarily childless all together (Greil, 1991; Bums *et al.*, 1999). Also, in some developing countries found within Africa and Asia, bearing a male child is seen as a significant economic advantage in such families. This is because a son is often seen as the future ‘bread-winner’ of the family and the main source of support to his parents at retirement and old age (Balunch, 1992; Molock, 1999). Therefore, it is not unreasonable for the involuntarily childless in these societies to display higher levels of psychological distress and trauma than those in the developed societies.

Another perceptible factor seen across diverse cultural groups with regards to fertility and childbirth is the issue of religious beliefs regarding the commandments and values set for producing children. Religious influence over fertility and infertility can be significant. Definitely among the Christians, bearing children is perceived as a divine fulfilment. The Old Testament discusses fertility and worthlessness and how those women who found favour with God immediately conceived without problems. For example, the Holy Bible talks about five women – Sarah, Rachel, Leah, Hannah, and Elizabeth – who conceived pregnancies after they were reportedly told they would not be able to do so due to their advanced maternal age (Cooper-Herbert, 1998); as a consequence of this connection between fertility and a woman’s value of favour with God, infertility is seen as punishment which shows that she is not able to attract God’s favour. Also, this implies that the more a person’s religious belief is, the more severe one’s expectation of the impact of being unable to conceive.

Culture which defines a person’s ethnic identity is a complex social phenomenon with a number of definitions. For example, according to Helman (2007), “culture is a patterned behavioural response that develops over time as a result of imprinting the mind through social and religious structures and intellectual and artistic manifestations”. In that regard, studies have shown how certain cultures diverge in how they ‘diagnose’ infertility. For example, the Greeks, Polish peasants and the Oceanic Turk Islanders believe that women should be held responsible for infertility (Greil, 1991). Same goes to certain cultural groups in some parts of Africa like the Aowin people of Ghana who hold a strong belief that infertility is brought upon

women by witchcraft; some Turks even believe that if a woman carries out hard manual labour then it will result in a 'bad stomach' which consequently causes her to be infertile; while the Ndembu of Zambia believe that infertility is caused by some ancestral powers of a dead relative (Greil, 1991).

In his review of the literature on infertility, Greil (1991) highlights the diversity of cultural beliefs and attributions held by different cultures and societies on involuntary childlessness. For example, the North African Somalians believe that infertility is caused by some astrological influences; while a certain tribe in the Central Celeb Island known as the Toradja – believe that infertility occurs because some ancestors are angered by an oversight of an incomplete performance of a couple's marriage rite ritual. Thus, the Toradja people believe that the ancestors could be appeased and infertility reversed by re-sanctifying the marriage again (Greil, 1991). But on the other hand, the Middle Eastern societies strongly believe that infertility is not caused by any ancestral or astrological powers rather, infertility is only an act of God that the couples' fate and destiny is to remain childless (Baluch *et al.*, 1998; Sewpaul, 1999; Greil, 1991).

As outlined above, if there are different cultural interpretations of what involuntary childlessness means, and if such beliefs are deeply imbedded in people's minds and behaviours, then it is not surprising when it inflicts its unique and culture-specific effect on such people's personal and social reactions (Greil, 1991). This is because an individual who believes that God is responsible for their ill-fate may show a different degree of psychological response than an individual who sees the problem to be medical. These different perceptions in infertility diagnosis could influence a person's help seeking behaviour.

Besides, with regards to some cultural and religious influences; if certain societies allow a man to dissolve his marriage or even take in a second wife due to the first wife's inability to bear children, then it is expected that the psychological effect will differ considerably when compared to those societies where such concessions are not given for a man to take another wife (Griel, 1991; Inhorn, 1996). Therefore, it can be argued that the beliefs and attributions of infertility as held by those who are challenged by it, their trust in medical treatments, and most significantly their strength in religious beliefs and the severity of stigma attached to involuntary

childlessness by the their society, all contribute towards the associated psychological impact on the involuntarily childless people (Baluch *et al.*, 1998). As such, it may be debatable that the only ‘common’ factor about the experience of infertility is the fact that involuntarily childless people all have a strong desire to conceive and bear children irrespective of their society or culture, and they all experience certain levels of infertility related stress such as anxiety, depression and frustration which are all associated with their ill-fate. However, the manifestations and facets of these psychological reactions can be argued to be experienced quite differently (Sewpaul, 1999).

Moreover, it cannot be concluded that people from different cultures and societies share the same reason for such feelings. Infact, it can be argued that the reason why some people experience more heightened psychological reactions of their infertility than others may be solely specific to their cultural beliefs and perceptions, and thus can only be understood by exploring and having scientific knowledge of what every culture and society hold about infertility or involuntary childlessness (Ahmed *et al.*, 1998; Molock, 1999; Furnham and Malik, 1994; van Rooij *et al.*, 2009).

3.6 Involuntary childlessness: experiences, coping and seeking solution

Some scholars have highlighted that bearing children gives women that much respected and acceptable adult status by their local communities in many developing countries (Hampshire *et al.*, 2012; Culley and Hudson, 2009; Hollos, 2003). A study in Israel by Remennick (2000) came up with a conclusion that the there is no such thing as ‘voluntary childlessness’; and many other researchers have made a similar observation in previous studies (Ibisomi and Mudege, 2014; Dyer *et al.*, 2002; Tabong and Adongo, 2013).

In their study in Hong Kong, Loke *et al.* (2012) explored the lived experience of sub-fertility among four married Chinese couples and three women. The researchers contend that their respondents spoke about their feelings of inadequacy and shame since they were unable to fulfil their desire for parenthood. For example, one of the respondents during an interview said, “*I started to doubt my identity as a ‘complete woman’ since all women should be able to give birth to babies. I really want to have a baby but I can’t*” (Loke *et al.*, 2012, p.507). Similarly, Reissman (2000) who explored the experience of stigma among childless women in India, demonstrates

that the visibility and surveillance of female infertility are central to the stigmatising process. Less affluent women in Ressimén's study found that village life is a difficult context to hide their fertility problems, whereas more affluent urban couples were to some extent shielded from intrusive questioning by their private, often nuclear families (Reissman, 2000).

Involuntary childlessness can cause unpleasant consequences to those experiencing it. Such people describe their condition as suffering from some kind of *social* disability; this is because in societies where childlessness is frowned upon, and adults who are in heterosexual long term relationships or married couples are expected to have children but then fail to do so, are generally seen as being deviant (Loftus, 2011). Involuntarily childless people often feel uneasy and tend to avoid the company of women with children as well as pregnant family member and friends (Greil, 1991). For example, Harris and Daniluk (2010) highlight in their recent study which explored the experiences of women who had spontaneous early miscarriage after their ART treatment, their participants reported being uncomfortable when in the company of pregnant women, following their pregnancy loss.

Feelings of guilt and blaming oneself are often regularly cited by individuals with reproductive difficulties. As Loke and colleagues posit, some involuntarily childless women have spoken about prioritising their education and career rather than settling down early into family life, report of feeling guilty for risking childlessness (Loke *et al.*, 2012). To further compound that, infertility and its associated treatment have been described as one of the most stressful experiences that women face with levels of anxiety and severe depression comparable to patients with cancer and cognitive heart failure (Cwikel *et al.*, 2004; Cooper-Herbert, 1998). Scholars have recognised infertility as a contributory factor to a diminished sense of well-being in the later part of a woman's life (McGuillan *et al.*, 2003).

In traditional settings such as those in Africa, it is quite common to find many couples having to run from 'pillar to post' in their desperate search for children. They move from one worship place to the other or from one herbalist to another who professes to have a solution for their childlessness. Some claim to seek unorthodox means towards overcoming the challenge while some even doubt the efficacy of Western medicine on the issue of infertility (Araoye, 2003). Even when these

numerous desperate searches for infertility abound in Africa, it may not be uncommon among the Black Africans who reside in some developed countries to seek unorthodox forms (non-Western means) of infertility solution such as going to church or taking herbal remedies. For example, in their infertility study in the Netherlands among migrant Ghanaian women, Yebei (2000) highlights that the involuntarily childless Ghanaian women did not stop to explore alternative treatment options like visiting a spiritualist and using herbal remedies since they could not afford the high cost of biomedical treatment or ARTs.

A study on the implication of infertility in Ghana by Fledderjohann (2012) demonstrates the extent infertile women go in seeking a solution to their predicament. The researcher expressed infertile women's views on frequently being advised to seek a solution to their childlessness in the church, and where the majority will always prefer to go to church for infertility solutions (Fledderjohann, 2012). There are also reports of alternative non-medical solutions to infertility in some social and cultural settings. Hudson (2008) highlights that for example, in Egypt, India, Pakistan and Vietnam, marrying a second wife is being described as a potential solution for infertile or involuntarily childless men, emphasising the significance of patrilineage in the family constitution. The author also reports that countries such as Pakistan, India and Mozambique, can have a religious or spiritual understanding of infertility, thus, visiting a spiritual healer is their way of trying to resolve their infertility (Hudson 2008).

Scholars who have explored infertility in the developing countries made some comparison regarding fertility treatment in developed and less developed countries and they concluded that there is a greater availability, acceptability and utilisation of alternative care system in the less developed countries (Kielman 1998; Okonofua *et al.*, 1997). There are narratives that in countries like South Africa and Zimbabwe, infertile patients have reported first visiting a traditional healer before deciding to go to the hospital for medical investigation and treatment (Dyer *et al.* 2004, Folkvord *et al.* 2005). Similarly, infertile women from the Bangladeshi slums according to Nahar *et al.* (2000) often consult with herbalist and spiritualist for their fertility problems as a common practice amongst them; this may be due to either financial constraint or their beliefs about solution to infertility. Therefore, the first action that those in these developing societies (who are unable to afford expensive and sophisticated

treatment) would normally do is to seek alternative treatments which are readily available and affordable to them.

3.7 Summary

This chapter presented the key conceptualisations of involuntary childlessness and how they have influenced the study. It maps out how different cultures can impact on the life of those who are involuntarily childless, in addition to the beliefs held by diverse societies regarding infertility. The chapter has briefly captured the experiences of involuntary childlessness and ways that those who have been challenged by it have tried to resolve their predicament with special emphasis laid among those from Black Africa. The next chapter discusses the methodology that was chosen and the research design employed to carry out this study.

Chapter Four: Research Methodology

4.1 Introduction

A post-positivist approach and a phenomenological research methodology were used to explore Black women's experiences/voices of involuntary childlessness. This chapter starts with a discussion of why this approach was deemed suitable for the answering the research question and meeting the objective. It also presents details of the research design, including the recruitment strategies employed for the collection of data for this study.

4.2 Choosing a methodology for inquiry

A qualitative (post-positivist⁵) approach was taken to answering the research question - what is the experience of involuntary childlessness among Black African women in Luton? The quantitative (positivist) approach (Lee, 1991; Levin, 1988) with a focus on objective knowledge was not seen as suitable as the research question lent itself to an exploration of women's experiences. Moreover, these experiences cannot be explored and described in terms of objective data that are not quantifiable (feelings, anxiety, fear) and statistically translated (Bawadi, 2009).

Since there is no experimental control of women who are studied in their natural environment, then there is a need for an approach which can give a richly detailed description of their experiences by analysing words rather than numbers. Post positivist studies have been criticised for being biased because the researcher will be 'too closely identified' with the study participants and different conclusions may be reached by other researchers who may try to explore the same study (Crossan, 2003). A qualitative research approach is now commonly used in health services research (Flick, 2000). A number of methodological approaches within the qualitative paradigm were considered before deciding on an Interpretative Phenomenological Approach (IPA).

As already stated above, this study used IPA. However, it is important to note here that other methodologies like grounded theory and ethnography were considered and

⁵ I am using post-positivism as defined by Clark (1998) to include the discovery of people's feelings, opinions and experiences from their own perspective, , rather than from that of the researcher (which positivists tend to do), so as to gain deeper understanding at the individual or group level experiences of the given phenomenon.

their suitability weighed-in before deciding on choosing the most suitable methodology to address the research question.

4.3 Phenomenology

This study takes a phenomenological approach to understanding the Black African women's experiences of involuntary childlessness. Phenomenology is derived from the Greek word *phenomenon*, meaning 'showing itself-in-itself' (Heidegger, 1962, p.54). Phenomenology is a research approach that involves exploring and describing a given phenomenon in its exact meaning for those experiencing it. According to Sokolowski (2000), it is an approach that requires the researcher to think about what the given lived experiences of individuals mean to them. Phenomenology tries to understand an individual's subjective experiences and perceptions from the point of view of that individual. This type of research approach is individualistic and provides the researcher with an opportunity to elicit information about a phenomenon regarding a person's unique experience.

The founding principle of phenomenological inquiry is that experience should be examined in the way that it occurs, and in its own terms (Smith and Eaton, 2012). It is important to note here that there are two dominant phenomenological approaches in qualitative inquiries that must be taken into account so as to attain an understanding; they are 'Husserlian and Heideggerian phenomenology'. Edmund Husserl (1859–1938), a German philosopher, was credited with the initial development of phenomenology as a philosophy, when he introduced the term 'phenomenology' in his book *Ideas: a general introduction to pure phenomenology* in 1913 (Moran, 2005). He described phenomenology as a recurrence of the lived world, the world of experience. He was concerned with revealing the essential qualities of phenomena as they appear in their context and how they arise.

Husserl linked the 'phenomenon' and 'being' in a coherent way. He argued that a phenomenon exists when a being experiences it. The Husserian tradition is epistemological in that it studies phenomenon as they appear to consciousness. When he developed the concept of the 'life-world', he sought to answer the question 'How do we know?' by describing the world as experienced by people.

In everyday life, people are busy involved in numerous activities in the world and even *take for granted* some experience of the world. Husserl reasons that

phenomenological inquiry requires that one should concentrate wholly on that which is often taken for granted and focus on that which an individual *consciously* experiences. Husserl invoked the technical word ‘intentionality’ which describes the link between the process that occurs in an individual consciousness and the object of interest for that process (Smith *et al.*, 2009). At this point, it is important to understand that Husserl’s main focus was with general processes, but in terms of specific situations, Husserl mostly focused on first-person processes – that is, what he had to do to himself to conduct phenomenological inquiry on his own experience whereas, psychologists or phenomenologists (Lavender *et al.*, 2009; Johansson, 2005; Fouquier, 2011; Hershberger, 2006; Afiyanti and Milanti, 2013; Todorova, 2011; Malik and Coulson, 2013) are more usually concerned with analysing other people’s experiences.

That takes us to the second approach in phenomenology ‘the Heideggerian phenomenology’. Martin Heidegger (1889–1976), who was Husserl’s student, took phenomenology further away from the *transcendental project* of the Husserlian approach by marking the beginnings of hermeneutics (the theory of interpretation) and existential emphases in phenomenological philosophy (Smith *et al.*, 2009). It is interesting to note that Heidegger’s move away from Husserl was not initially a move away from phenomenology. To a certain extent, he believed that his work was more phenomenological than Husserl’s. For Heidegger, Husserl’s phenomenology was too theoretical and too abstract (Smith *et al.*, 2009), whereas as Moran (2000) notes,

“Phenomenology is seeking after a meaning which is perhaps hidden by the entity’s mode of appearing. In that case, the proper model for seeking meaning is the interpretation of a text and for this reason, Heidegger links phenomenology with hermeneutics. How things appear or are covered up must be explicitly studied. The things themselves always present themselves in a manner which is at the same time self-concealing” (Moran, 2000; p.229 cited by Smith *et al.*, 2009).

Heidegger shifted his philosophical focus of phenomenology from Husserlian epistemology ‘how do we know what we know?’ to Heideggerian ontology by studying the nature and relations of being ‘what does it mean to be a person?’

(Lavery, 2003). While epistemology seeks to discover what can be known about the world, ontology concerns itself with what exists. Heidegger was more interested with the meaning of lived experience and existence. He renounced the subject–object schism and directed his attention to the ontological condition that involves the understanding of being rather than the relationship of the knower to the known (Heidegger, 1962).

One significant argument that Husserl had, was that researchers should suppress their natural attitudes or suspend naturalistic presuppositions concerning knowledge, instead they should focus on ‘clarifying the essence of cognition’ (Husserl, 1964, p.18). Heidegger countered Husserl’s argument by saying that researchers are already in the world and that it is impossible to categorise ourselves. He argued that by being in the world, researchers interact with others, not as observers but as beings associated with the same world as that which is studied or observed (Heidegger, 1962).

Therefore, the conceptual approach used for this study is driven by the Heideggerian hermeneutic phenomenology. This methodological approach seems more suitable for this study because it gives the researcher the opportunity to explore an individual’s personal experience through direct interactions with them in their natural environment thereby creating rich, detailed data that will allow for a better understanding of their subjective experiences (Rees, 2003). As this study is rooted in the principles of hermeneutic phenomenology, this means that the researcher engages in an *interpretative* process. Interpretation is an attempt to bring to light hidden meaning so as to obtain a comprehensive understanding of that which *seems* hidden. This interpretative phenomenology inquiry therefore, aims to generate a deep understanding of the experiences of involuntary childlessness among the Black African women.

4.4 Reason for using a phenomenological approach

The aim of the phenomenological approach in this study is to uncover, express, illuminate and describe the meaning of individual subjective experiences from the perspective of the individuals involved. Phenomenology which is the study of the structure of different kinds of experiences such as perception, imagination, desire, volition, bodily awareness, and social activities, offers insight with regards to how

people in a given situation make sense of a given phenomenon (Brocki and Weardon, 2006).

Lester (1999) argues that since phenomenological approaches are underpinned by individual subjective knowledge that lays emphasis on the importance of a person's viewpoint and interpretation of a given phenomenon, they are great when employed for the understanding of people's subjective experiences as well as what motivates or drives them thereby, bypassing the cluster of *taken for granted* assumptions and common knowledge. This approach is quite effective at uncovering and making sense of the experiences and perceptions of individuals from their own viewpoints, thus at challenging ordinary assumptions that would commonly be made by others who may not have better idea of the phenomenon (Lester, 1999).

As a phenomenological method of inquiry strives to elicit, illuminate, uncover and generate detailed information about the inner essence of a person's cognitive processes with regards to a given phenomenon, this means that the end product of such inquiry should bring to fore a detailed description of the individual's experience in a compelling and convincing way that the reader will have a strong sense of "*now I understand what it is like to experience this phenomenon*" (Smith *et al.*, 2009). Merriam captures it accurately that "phenomenological approach is well suited for studying affective, emotional, and often intense human experiences" (Merriam, 2009, p.26). In addition, unlike grounded theory which employs theoretical sampling that seeks to continue gathering data till no new information emerges; phenomenological methods such as Interpretative Phenomenological Analysis (IPA) aim to look for participants that will allow the illumination and elucidation of a given research question. Brocki and Weardon (2006) argue that grounded theory aims to establish claims for a larger sample size while phenomenological research are more interested in analysing divergence and convergence in small sample sizes.

4.5 Phenomenology as a methodology

As discussed above, this research takes a phenomenological approach to answering the research question. Although there are a number of studies looking at infertility, they focussed on the epidemiology and management of infertility among the White communities mainly in the USA and Europe using a quantitative approach (Oakley, 2012; Bhattacharya *et al.*, 2009; Bolsoy *et al.*, 2010; Chachamovich *et al.*, 2009;

Hassa *et al.*, 2005). Qualitative studies in the UK have tended to focus on the experiences of the South Asian community (Culley *et al.*, 2007 Hudson, 2008). There is little available literature on the experiences of the Black African communities in the Western societies, and as qualitative research allows for an in-depth investigation on a topic, it was seen to be the most suitable approach in exploring the experiences of involuntary childlessness among the Black Africans in the UK.

Qualitative research methods are popularly used for sensitive areas of research such as the current study. There are different types of qualitative research methods but they all share a common approach which tend to focus on phenomena that holds subjective meaning to it, and also tend to ask participants to share issues which are profound, personal and perhaps challenging to them (Lee, 1993). Such methodological approach seeks to establish non-hierarchical forms of relationship between the researcher and the study participant by having at heart the interest and concern of the participant, sharing the control over the flow of information gathered from data collection to publication while maintaining a good level of anonymity and confidentiality when disclosing sensitive information (Lee, 1993 cited by Carroll, 2012).

Researchers who are involved in exploring sensitive research have a duty to use their professional, physical and emotional selves as a research tool for building rapport, analysing emotions and interpreting data during the field work (Oakley, 1981). As the research process entails in-depth interactions and self-disclosure during interviews, it is important that the researcher is an active listener, express emotion and show support/care when interacting with the research participant as these are all vital features of this nature of research (Carroll, 2012). For these reasons, IPA suits best for an inquiry which seeks to understand the lived experiences of those faced with the challenges of childlessness.

4.5.1 Relationship between phenomenology and IPA

Phenomenology is rooted on the principle that reality is made up of objects and events based on the way these are perceived and interpreted in an individual's conscious state of mind and not anything out of their conscious state (Smith *et al.*, 2009). Therefore, IPA is phenomenological because it aims to investigate an

individual's subjective account of a given phenomenon as against making attempt to generate an objective account of the said phenomenon. This makes IPA a key theoretical measure of phenomenology (Smith *et al.*, 2009).

IPA is interpretative because in order to explore and gain a better understanding of an individual's subjective account or experience, IPA reckons that a researcher can only achieve that aim based on his/her own previous knowledge (which may have been gained through experience, existing literature or previous research) which is needed to make sense of the individual's personal account through the process of interpretative activities (Smith *et al.*, 2009).

4.5.2 Relevance of IPA to this study

Taylor (1985) maintains that at the heart of IPA is the conception that people are known to be self-interpreting humans. In other words, people are constantly in the act of giving different meanings and interpretations to objects and other people around them, and this interpretative activity captures the phrase 'sense-making'. Therefore, the main purpose of IPA is to make detailed analysis, and bring to fore the way people *make sense* of their lived experiences (Smith *et al.*, 2009; Smith and Eatough, 2012).

IPA studies are interested in exploring intense personal issues, or concerns that are of great magnitude for a participant who is currently going through that issue; or an event that had happened at a crucial phase of the participant's life. Most often, the type of phenomenon that IPA explores are about issues that affect a person's identity and self-image as elaborative and rigorous analysis of an individual's record of a significant experience mostly affects their sense of self (Smith *et al.*, 2009; Smith and Eatough, 2012). It has the distinct advantage of being naturalistic, inductivist, constructionist, and interpretative (Bryman, 2001). Moreover, it employs the use of natural settings as the source of data and the researcher's role is to use 'empathic neutrality' in the observation, description and interpretation of phenomena, in terms of specific meanings that people bring or assign to them (Patton, 1990). IPA provides an experiential qualitative tool to explore experiences from a phenomenological approach.

IPA creates an opportunity for people who are marginalised or silenced, to be able to voice out their concerns and be heard. According to Todorova (2011), when

employing IPA to explore different socio-cultural contexts, the author opines that IPA is capable of allowing a researcher the opportunity to get closer to his/her participant by listening carefully in order to understand their concerns whilst gaining their trust to interpret the participant's meaning of that account without deconstructing their language. Thus, given the philosophical foundation of this study, the principal objective of this study is to explore the complex, dynamic and progressive component of human experience in relation to involuntary childlessness; it is felt that the IPA is most the appropriate method for the research.

4.5.3 Challenges of using IPA

The evidence base highlights that there are two broad challenges of using IPA methodology:

Theoretical challenge: IPA is inductive in nature just like some other qualitative methodologies since it involves methods that allow unanticipated or unpredicted themes to emerge during analysis therefore (Griffiths, 2009). Thus, IPA does not generate specific hypotheses based on the extant literature but allows for the development of broad research questions which tend to lend themselves to the collection of extensive data. Moreover, though IPA involves the indepth analysis of data drawn from small sample sizes, and faces the criticism of non-generalisation; however, results from IPA can be discussed in relation to the broader extant health research literature (Smith *et al.*, 2009; Griffiths, 2009).

Methodological challenge: Apart from the fact that it generates so much data which is narrative focussed; IPA has been criticised for the amount of space it allows for an in-depth contextualisation of the participants' narratives, whilst striving to uphold the principle of *coherence* (Todorova, 2011). The "coherence of a piece of project is achieved when the research fits the postulations of the theory, when work is carried out in a synchrony of epistemology, methodology and method" (Todorova, 2011).

For instance, some studies have been highlighted that were faced with such challenge which focuses on how meanings of health intersected with gendered identities (de Visser and Smith, 2006; Lavie and Willig, 2005; Todorova and Kotzeva, 2006). Research by Todorova and Katzeva (2006) who used IPA to explore the experience of infertility in their study argued that they were faced with a difficult decision of preserving the coherence of their chosen research approach while trying

to define the huge implication of restrictive socially constructed pronatalist cultural definitions of femininity and masculinity of those with reproductive failure.

This difficulty may be due to unnecessarily focusing and strictly adhering to instructions of the research method at the expense of sacrificing content and important elements of the study (Todorova, 2011). Moreover, it can also be concerned for commensurability (concepts are commensurable if they are measurable by a common standard) of epistemological and theoretical stances, thereby aiming to preserve a key component of a qualitative research – coherence (Todorova, 2011).

Second, IPA studies are criticised for their inability to reach a point of ‘data saturation’. Turner *et al.* (2002) in their study which explored experiences of ex-professional footballers’ who lived with and managed osteoarthritis, recruited 12 participants in their study as they felt that they have reached a point of data saturation in their study. However, saturation is a problematic concept in an IPA context (Brocki and Weardon, 2006). IPA is continual or iterative in nature whereby transcripts are analysed continuously in view of new occurring meanings or explanations that are generated from other sources. According to Brocki and Weardon (2006), “IPA process in theory means continue *ad infinitum*”. They authors contend that a qualitative inquiry should aim to accomplish the type of understanding that justifies its achievement of coherence; and perhaps a point when the researcher can confirm that he/she has achieved that aim while telling a compelling and convincing story, that the analysis may be deemed completed (Brocki and Weardon, 2006).

4.6 Research design

The sections above have highlighted why IPA was considered to be the most suitable approach for answering the research question. The sections below turn attention to the research design.

4.6.1 Debate about suitable sample size for IPA study

Interpretative phenomenological studies commonly recruit small sample sizes since the purpose is to find a sample with shared characteristics where similarities and differences can be observed in great depth (Smith *et al.*, 1999). Moreover, the

researcher's sample selection will also depend on those who are willing to participate in that study.

Smith *et al.* (2009) note that IPA studies can be carried out with samples sizes ranging between one and nine, but not very suitable with larger sizes of over fifteen. For example, Johansson and Berg (2005) in their infertility studies recruited and interviewed seven women who were still childless two years after the end of their IVF treatment. This is because IPA aims to present an indepth and idiographic exploration of the subjective account of the participant's experience which can only be achieved with a small number of participants or cases. Sample size of five or six is often recommended as a manageable number for a student research (Smith *et al.*, 2009). In other words, it can be more difficult to use a large sample size for IPA studies.

The main aim of IPA is to focus on indepth accounts of a person's subjective experience; which means, IPA is concern with the quality and complexity of the phenomenon which is being researched and benefits from a concentrated small sample size. Some authors have argued that in their own practice e.g. in psychology, a sample size of three is commonly used by undergraduates or postgraduates at MSc level for their research project (Smith *et al.*, 2009). Having a sample of size of three allows the researcher to pay attention to tiny details which may reflect points of divergent and convergent. However, the authors said it was more difficult to give a number for PhD project as the case may be, which are obviously on a different scale but could range from a single case study to a larger sample of eight participants or drawn from one of the bolder designs (Smith *et al.*, 2009).

Firstly, for example, Hudson (2008) recruited a large number of participants for her PhD research which explored infertility perceptions and experiences among the South Asian communities in the UK. Though her study was divided into two manageable phases; phase one – 13 focus group discussions with a total number of 87 participants, which was gender specific; and phase two – in-depth interviews with 15 involuntarily childless women. Secondly, another study that explored infertility perceptions and experiences was carried out by Tabong and Adongo (2013) in Ghana. These authors employed 3 focus group discussions (one each for involuntarily childless women, women with children, and men with children); and a

further 15 units (where a unit here signifies that some men were married to 2 wives each) of married childless union with a total number of 33 participants to collect data for their study. Thirdly, an earlier infertility study in Wales carried out by Owen (1986), who explored the desire for children among involuntarily childless couples, recruited 30 couples for a PhD study. Fourthly, Mogobe (2005) explored the experiences of childlessness among 40 involuntarily childless women in Botswana. However, *all* these mentioned studies utilised other forms of qualitative research methods for their studies and not IPA because it would have been classified as *too large* for an IPA study. On the contrary, a number of studies in the area of fertility challenges that have used the phenomenological approach, have recruited a manageable size of participants as suggested by Smith *et al.* (2009) to explore the above-mentioned phenomenon.

For example, Loke *et al.* (2012), who explored the experiences of infertility in Hong Kong, recruited 11 involuntarily childless participants for their in-depth interviews – 7 women and 4 men. Another IPA study on infertility was done by Kilbride (2003) for her PhD study who recruited 10 involuntarily childless couples (9 white British and 1 White Spanish) to participate in her study of *how couples communicate their fertility problems* all contacted via a fertility clinic. Crete and Adamshick (2011) explored the lived experiences of 7 women who were suffering from polycystic ovary syndrome (POS) in the USA; Hershberge and Kavanaugh (2008) explored the lived experiences of 8 pregnant donor oocyte recipient women in the USA; Harris and Daniluk (2010) explored the experiences of 10 women who experienced spontaneous pregnancy loss (miscarriage) after conceiving through ART; and Rapport (2003) recruited 11 women to explore their beliefs and experiences being potential egg share donors.

However, there are IPA studies other than those that explored infertility experiences that also targeted a smaller sample size for their study such as: migrant Arab Muslim women's experiences of childbirth in the UK by Bawandi (2009) – recruited 8 women; experiences of adoptive mothers by Harris (2012) – recruited 9 women; transwomen's memories of parental relationship by Dearden (2009) – recruited 6 participants. All these studies were PhD research.

All the above-mentioned studies recruited small samples for their phenomenological studies except for an IPA study by van Rooij *et al.* (2009), who recruited a larger sample size (10 couples and 9 women = 19 participants) into their study, to explore the experiences of involuntary childlessness among Turkish migrants in the Netherlands as opposed to the recommended small sample size (Smith *et al.*, 2009).

4.6.5 Rationale for chosen sample size

There has been a growing body of debate on '*how many qualitative interviews is enough?*' According to Brannen and Nilsen (2011), there is no rule of thumb in how many qualitative interviews is enough. Firstly, selecting a few participants may be sufficient enough for a research project especially for hard-to-reach groups of people or communities (Alder and Alder, 1987) such as those of the current study. Here, Alder and Alder argue that a sample size of not more than twelve may allow researchers to delve deeply into the phenomenon they wish to explore. They also argued that a sample of loosely around 30 people offers the advantage of not being restricted to a very small sample, but also do not want to be overwhelmed by the difficulty of an endlessly data collection and analysis; specifically when researchers have but a limited time to complete their study (Alder and Alder, 1987; Akizuki and Kai, 2008; de Kok and Widdicombe, 2008). Nonetheless, Alder and Alder (1987) quipped that a graduate committee consisting of both qualitative and quantitative researchers may not easily agree to the same sample size of a particular empirical study.

Therefore firstly, when taking into account the amount of time a research of this nature usually takes, the trouble in accessing the study participants, how daunting it can be to transcribe several hundreds of hours of interview recordings, and the compulsive publications that researchers have to make, it is better to collect a reasonably manageable data even though its challenges cannot be overruled (Alder and Alder, 1987).

Secondly, to determine a successful sample selection, Brannen and Neilsen (2011) posit that the sample size is not necessarily the problem, nor the assignment of people into groups (such as those in FGDs) that is so crucial, but the ability to include unique cases; this case may be a person whom it may not be easy to invite to participate in an in-depth interview or join in FGDs. Therefore, these scholars

propose that the key thing to consider when deciding on the number of participants to be interviewed or the sample size for a study should depend on the purpose of the study (Brannen and Neilsen, 2011).

Thirdly and most importantly, life story research which seeks to offer insight into people's personal experiences using IPA is most expected to require a small sample size due to the great depth of methodological analysis which is often required (Bryman, 2012) Thus, generating a large amount of data for such research will only make the researcher not only lose focus, but also lack depth of the fine-grain analysis required of an IPA study.

Finally, consistent with Bryman (2012) and as already stated earlier-on in this section, IPA studies have no specific answer to the number of participants that should be included in the study but Smith *et al.* (2009) argue that there are IPA studies with a sample of only one case, and those with over fifteen participants. This is because IPA is committed to providing detailed interpretative accounts of cases and based on quality/depth instead of quantity. Therefore, based on all these highlighted reasons, the current study recruited 8 involuntarily childless or infertile Black African women for this study.

4.6.6 Sample frame

A sampling frame is a list or map that identifies most units within the target population; there are basically two types of frame available for social research: the '*existing frame*' and the '*constructed frame*'. The *existing frame* usually comprises of records which were produced for administrative purposes, e.g. benefit records. The second type of sampling frame is known as the *constructed frame* which social researchers can use when there is no *existing frame* in place. There are a few constructed frames available: focussed enumeration, organisation screening method and advertising/snowballing (Lewis-Beck *et al.*, 2004) – this study used the advertising and snowballing constructed frame because the target sample are hard-to-reach persons from one of the minority communities in the UK. The following sections detail the research question, methods and strategies employed to achieve it.

4.7 Research question

The research question for this study is:

What is the experience of involuntary childlessness among the Black African women in Luton?

The specific methods used to answer the research question are presented below.

4.7.1 The sample

This study employed one-to-one in-depth interviews with Black African involuntary childless women using a topic guide (Appendix 1). It explored in-depth information about the meaning that involuntary childlessness brings to the lives of women. Participants for this study have been trying to conceive a pregnancy or maintain a pregnancy for at least one year and above and are within the reproductive age group 25–49 years. This age range was selected based on previous research. Several researchers exploring infertility and involuntary childlessness have recruited participants with ages ranging from 16–70 years (Culley *et al.*, 2007; Simpson *et al.*, 2011) amongst British South Asians; 21–48 years (Mogobe, 2005; Fledderjohann, 2012) amongst Botswanans and Ghanaians, respectively; 25–49 years (de Kok and Widdicombe, 2008; Hollous *et al.*, 2009) amongst Malawians and Nigerians, respectively; and 30–53 years (Parry and Shinew, 2004; Payne *et al.*, 2011) amongst Caucasians in the USA and women from New Zealand, for their studies depending on the main aim and purpose of their research.

However, from close observation, researchers recruiting participants from Black African countries tend to recruit participants who are within the reproductive age range 21–49 years old, unlike studies that targeted the South Asians which tend to recruit participants who are far younger – 16 years. On the other hand, studies that explored the infertility experiences of people from White and Caucasian backgrounds tended to recruit participants who were older than the first two groups even though they were still in their reproductive age.

It is important to note here that none of the participants recruited for this study were born in the UK. At the time of the fieldwork four of them had been living in the UK for over 20 years and the remaining four had been living in the UK for between 4 and 7 years. Three of the women mentioned that they first sort medical attention for their inability to conceive in their home country before coming to the UK while others had their first and subsequent fertility care in the UK. It is interesting to note that despite some of the participants being here for a significant amount of time they

still subscribed to pro-natalist views which were embedded within African culture. Evidence suggests that length of stay influences socialisation (WHO, 2010) but in the case of infertile African women in this sample this was not the case.

Eligibility criteria

The inclusion and exclusion eligibility criteria were as follows.

Inclusion:

1. Participants self-defined as being of the Black African ethnicity;
2. They have been infertile or involuntarily childless (according to the NICE 2004 definition of infertility as defined in chapter one) that is; those who have never been able to conceive or carry a pregnancy to full term – 9 months successfully; or miscarry – simultaneous abortion; or may have lost the baby through stillbirth/child death;
3. They are all married or in a long-term heterosexual relationship;
4. They all live in Luton with post code range LU1 to LU4;
5. They are all women 25–49 years of age at the time of recruitment;
6. They could communicate proficiently (understanding and speaking) in English;
7. They willingly share their experience of involuntary childlessness.
8. Participants were not restricted due to socio-economic status as they included those who are employed and un-employed

Exclusion:

1. Those who did not self-define as being from any of the Black African ethnicities;
2. Those who have conceived naturally (or through assisted conception) but have not successfully conceived a subsequent pregnancy (i.e. secondary infertility);
3. Those who may have had child(ren) from a previous sexual partner but are not able to have any in their current sexual relationship;
4. Those who were childless by choice.

Recruitment

Participants were selected purposively (Bowling, 2009) for the in-depth interviews. This is a sensitive area of research and there is evidence that it is difficult to recruit for sensitive research. For example, Farland and Caron (2013) who explored the long-term impact of infertility among menopausal women in New England argued that due to the sensitivity of the subject area, it was particularly difficult to identify these women to be interviewed. Notwithstanding the sensitive nature of this study, the aim was to recruit women who have been infertile or involuntarily childless for over one year.

Challenges and contingency of recruitment

The challenges for recruiting people from ethnic minorities are documented in the wider literature (Carter-Edwards *et al.*, 2002; Sullivan-Bolyai *et al.*, 2007; Elam and Fenton, 2003; Sheldon *et al.*, 2007; Foster, 1998). Recruiting participants to take part in studies are known to pose a significant problem to researchers of population health research irrespective of what the study is about, its methods or outcome (Leung *et al.*, 2013). The successes of recruiting through multiple methods have been previously recorded. Webster *et al.* (2012) evaluated the techniques used in a pregnancy study and suggest that employing multiple techniques such as advertisement and word of mouth did produce a more successful outcome.

Therefore due to the sensitive subject area of investigation with the known fact that the target population places such great importance on motherhood and family, this study proposed to recruit participants from Pentecostal churches, University of Bedfordshire announcement board (BREO), infertility support online forums, and word of mouth and personal contact. Adverts (see Appendices 5, 6, 7 for all the recruitment adverts) were placed on the strategic locations to enhance recruitment. However, word of mouth and personal contacts were the only methods that were effective and efficient in recruiting the study participants. The researcher invited eligible participants through her personal contacts as well as snowballing into the study. The most commonly reported recruitment strategy for this nature of research is through word of mouth (Loke *et al.*, 2012; Hollos *et al.*, 2009; Mogobe, 2005; Simpson *et al.*, 2011) which is also considered the most effective. Hudson (2008), who explored the experiences of infertility among British South Asian communities,

mentioned that personal contacts built up over the course of carrying out an earlier phase of her study were invaluable in recruiting participants for in-depth interviews.

After waiting for two weeks without any success in recruiting participants via the other recruitment avenues, the researcher used her personal contacts to invite three women whom she personally knew were struggling with involuntary childlessness to participate in the study. The woman, who happened to be interviewed first, through word of mouth and snowballing, helped to invite two more women to participate in the study. The other two women from the researcher's contact also reached out to other involuntarily childless women whom they knew (both friends and relatives), to participate in the study. That was how the researcher was able to have eight eligible participants to partake in the study. It is important to highlight here that even with the word of mouth and snowballing, it was not without its challenges. This is because there were participants who refused to participate even though they were referred to take part by those who had already participated. Three eligible involuntarily childless Black women turned down their invite by saying they were not in the good mood for such interviews.

It is important to note that the decision of the researcher to recruit in Luton alone was because Luton is the main study and residential site of the researcher. This was a practical measure to minimise both the cost and time it could take to conduct the study.

4.7.2 The topic guide

Semi-structured interviews with a topic guide designed by the researcher, who followed guidelines set out by Smith *et al.* (2009), was employed to facilitate the in-depth exploration of the participants' experience of involuntary childlessness. Developing a topic guide requires one to think clearly about what is expected to be included in the interview. Specifically, it enables one to plan for any difficulties that might be encountered. These difficulties may include the phrasing of complex questions or the introduction of potentially sensitive topics, and thinking through possible referral mechanisms to therapeutic support such as specific agencies, counselling or help-lines.

Moreover, it also helps the researcher to prepare for more reserved participants who might be less forthcoming, and might prefer a slightly more structured approach.

Without prior thoughts to possible questions, such an interview is likely to make the interviewer more anxious, and a less effective interview may ensue (Smith *et al.*, 2009; Draper and Swift, 2010). Therefore constructing a topic guide helps the virtual map for the interview, which can be drawn upon if, during the interview itself, things become difficult or stuck. As a consequence of this preparation, the researcher is able to be a more engaged and attentive listener and a more flexible and responsible interviewer. The topic guide was constructed in such a way that it covered some infertility themes which were highlighted by previous studies discussed in chapters two and three. Questions on the topic guide explored the participants' experiences of involuntary childlessness, which included issues of stigma (Cousineau and Domar, 2007; Akinloye and Truter, 2011; Pfeffer and Woollett, 1983; Miall, 1986); isolation and avoidance of pregnant women and children (Greil *et al.*, 2011; Loke *et al.*, 2012; Lampman and Dowlin-Guyer, 1995); excessive pressure on involuntarily childless women (Bolsoy *et al.*, 2010; Pottinger *et al.*, 2006; Leonard, 2002); disclosure of infertility to others (Miall, 1986; Loke *et al.*, 2012); and solutions and ways of coping with infertility (Fledderjohann, 2012; Araoye, 2003).

At the end of the topic guide, there was a request for participants to fill out a demographic questionnaire (see Appendix 3) which asked questions such as age, ethnicity, marital status, educational and occupational status. Interviews lasted 30-90 minutes depending on the interview atmosphere and the willingness of participants to tell their *story*. Interviews were all audio recorded and any other additional information collected during the initial introductory part of the interviews were written down on the researcher's fieldwork diary (Larkin *et al.*, 2006; Biggerstaff and Thompson, 2008). Silverman (2000) argues that in keeping a diary, one is not only recording data but also analysing it.

The fieldwork diary consisted of descriptive data for each participant, the informal conversation before the commencement of audio-taping and personal thoughts/ideas. These notes in the diary supplied the contextual data on each woman's life. They were helpful during the analysis and interpretation process, and also when revisiting the data several weeks after completion of interviews.

4.7.3 Data collection

The face-to-face, semi-structured interviews were carried out at a chosen place and time most suitable to those interested to participate in the study, which was in their home and all interviews were recorded using a digital recorder, except for one interview where the participant did not want it audio-recorded but handwritten. The researcher wrote down the participant's narrative on a fieldwork diary. Verbatim transcriptions were carried out soon after the interviews. Smith *et al.* (2009) recommend that researchers should consider their personal preconceptions and what they experienced whilst researching when they reflect on their findings. The following important observations were made during the research process.

Setting the stage

As a researcher who did not previously have practical experience in conducting in-depth interviews but had only had been involved in quantitative data collection, this was an opportunity to put all the theoretical skills into practice. The first interview with the study participant set the stage to utilise all skills learned from textbooks on how to conduct in-depth interviews in qualitative research. It was observed that after the initial exchange of pleasantries with the participant, and having gone through the purpose of the study using the participant information sheet, it was obvious that the first participant (Theresa) became a bit too self-conscious and tensed when the audio recorder was turned on. This made her stammer in her first few sentences, creating a rather tense and very formal atmosphere. This moment of awkwardness was immediately spotted, and the researcher reassured the participant that it was only a discussion of a personal experience rather than an intense kind of 'job' interview. Smith *et al.* (2009) encourages researchers to make effort in establishing rapport with their participants, right from the start. This technique helped to relax the atmosphere, and a good rapport was quickly established. Subsequent interviews were reasonably easy and smooth with interviews lasting between 45 to 90 minutes.

Insider versus outsider: caught in-between

According to Dwyer and Buckle (2009), the issue of the researcher being an insider or outsider to the group under investigation is an important one that has received increasing attention from social scientists, often because they find themselves conducting research in a group which they are not a member of. The authors further

argue that whatever role a researcher may play during any study be it an insider who shares same characteristics as their participants, or an outsider to the community studied, such role remains an important feature of that study (Dwyer and Buckle, 2009).

Serrant-Green (2002), a Black African-Caribbean researcher in the UK, wrote her personal experience of being both an insider and an outsider researcher exploring issues in the Black communities. The author suggests that researchers studying Black communities are encouraged to recognise their cultural position in relation to the group and account for the expected tensions in the research. The on-going debate about the status of the researcher in conjunction with the researched, considers how closely researchers must identify with their study group in order to produce quality research (Serrant-Green, 2002). Initially, it will seem that researching the Black and ethnic minorities support the position of the researcher as an insider which obviously comes with some benefits, especially in academia; however, proponents of the outsider debate are able to raise similar convincing arguments (Serrant-Green, 2002). Kaufman (1994) notes that individuals might feel more at ease in discussing aspects of their lives with strangers who are not part of their social circle than with those who they might interact with at other times. This situation was observed in the current study. It was apparent that some participants were not comfortable to disclose in detail what type of fertility treatment and procedures they have had done, most especially when it has to do with ARTs.

4.7.4 Ethical considerations

Avoiding harm to participants as much as possible is an important duty of all researchers regardless of what they may be investigating (Social Research Association; SRA, 2002) and as such, consideration was given to the British Psychological Society Code of Human Research Ethics (BPS, 2014) and the University of Bedfordshire. The Ethics Approval confirmation provided by the University of Bedfordshire can be found in Appendix 9.

Various ethical issues were considered in case issues occurred during the study and ways proposed to handle them if they did arise. Detail is given here on how informed consent was sought, how confidentiality was maintained and how the participants'

wellbeing was thoughtfully considered in case of distress during or after the interviews.

Issues around subject matter

As the research topic may be classed as ‘sensitive’, care was taken when discussing issues that may upset participants. This happened to one participant: she became upset while narrating her story; the interview had to be discontinued until some other time when she felt she was composed and ready to narrate her experience. However, the participant texted the researcher the following day to say she will not be able to continue with the interview any longer, but she was happy for the bit she had discussed to be used for the study. All participants for the study were provided with contact details (see Appendix 8) on how to get help or further advice and counselling if they felt unhappy or distressed as a result of the interview by signposting them to specialist counselling organisations such as the UK’s leading infertility support network, Infertility Network UK.

Matters around the principal researcher

The researcher used a personal fieldwork diary to help record and monitor her own experiences as well as other minor but important events with the participants which could not be captured by the audio recorder during the course of all interviews (Woods, 2006) as the data collection stage of the study progressed. This is recognised as a positive intervention (Fontes, 2004). The researcher kept close contact with her supervisory team through the course of the field work so as to get adequate support where necessary and debriefing (in the case of an incident) should she encounter problems during the field work.

Confidentiality issues

All data and information gained were anonymised once collected, and treated in confidence and in accordance with data protection legislation by separating all identifying details of the participant from the data and then coded with a ⁶distinctive identifier (e.g., participant 1 on 21th August 2015 is 21082015), this protects their personal identity and information shared with the research team during the course of the study. Also, all research findings will only be published in anonymised form as

⁶ When more than one interview was conducted on the same day, the distinct identifier had an additional letter to the date (e.g. 21082015A).

the researcher will treat all information collected with confidence and adhere strictly to the British Psychological Society Code of Human Research Ethics (BPS, 2014).

Obtaining informed consent

Once the selection of eligible participants was completed, each participant was issued with an Information Sheet (see Appendix 4) which details the purpose of the study including confidentiality, the risks and benefits associated when partaking in the research, the right of withdrawal, and dissemination of research findings. The information sheet included contact details of the researcher and her supervisory team for any further information or query that may arise. Information sheet and consent form (see Appendix 2) were always given to participants to read, fill out and sign before commencing interviews. This was normally done after revisiting the consent form before the start of the interview just to ensure that the participant had a complete understanding of the study, and then the establishment of rapport and trust ensued. As the study proposed to audio-record all interviews, permission to record was also sought before recording. Where there was an objection to audio-recording, the researcher wrote down the interview on her fieldwork diary, though this hindered the flow and rapport of the interview as earlier described.

4.7.5 Process of data analysis

Transcription

The researcher transcribed all the interviews verbatim including all questions asked and comments made during the interview. Transcribing the interview without the employment of an outside agency allowed the researcher a good level of mental engagement with the data to be able to recall things transpired during the interview process such as gestures, body language and even the interview atmosphere. Smith and Dunworth (2003) argue that when researchers subsequently read interview transcripts, it allows them to mentally hear and recall their participants' voices because this contributes to achieving a more complete analysis. The procedure of rereading and reliving the interview transcripts was experienced during the first step of the IPA data analysis.

Analytic Process

The researcher followed Smith *et al.* (2009) seven steps of IPA data analysis. The authors suggest that all transcripts should be individually treated because of the idiographic nature of IPA. Therefore, all transcripts were analysed individually from the first participant to the last accordingly. All analyses were done manually on the computer using MS Word for easy manipulation of words and tables. The researcher preferred to work around the data with a computer rather than handwritten materials, from transcription to coding, and all other subsequent forms of analysis to show the transparency of data handling (Smith *et al.*, 2009) and the ease it afforded to share the whole analytic processes with the research supervisory team. Once initial notation or contextual coding (see Appendix 11 for an example of this stage) were done, the emergent themes were identified and developed further (see Appendix 12 for an example of clustered themes). At this point, the purpose of the analysis was to have a better understanding of what the participant was saying by transforming the initial notation to something with a precise meaning. According to Smith *et al.* (2009), this is the stage that allows the reflection of the emergent themes to represent both the original words of the participant and the researcher's interpretative meaning.

After analysing all the transcripts in the manner described above, a table was formed where all the emergent themes were typed chronologically onto the left-hand column of the table with a matching quotation from the original text from the transcript typed

on the right-hand column, equally showing the page and line number where the quotes were extracted from the transcript on the middle column of the table (see Appendix 13). The next step was grouping of themes with similar meaning and concept together under newly formed super-ordinate themes. After several attempts at finding the most suitable name to capture each group of themes and the essence of the phenomenon, three super-ordinate themes with corresponding sub-themes were developed (see Table 5.2) *'the vulnerable self'*, *'self and the social world'*, and *'coping with involuntary childlessness'*.

After completing each stage as outlined above for all transcripts, the next stage was to search for similar patterns across each individual case whilst keeping in mind the idiographic nature of this process by generating a master table of themes (see Appendix 14). This stage captures at a glance the participants' shared experiences.

4.7. 6 Achieving rigour

According to Madill *et al.* (2000), researchers who employ qualitative approach have received criticisms for flexibility of subjective analysis. Lemon and Taylor (1997) argue that phenomenological processes do not typically rely on the traditional qualitative approaches which tend to have at its fore the reliability, objectivity and validity of research findings, rather phenomenology focuses more on the quality and rigour of the research by applying the appropriate research tools in order to meet the research objectives. Moreover, Stiles (1993) addressed the concern regarding quality and rigour in qualitative studies, and maintain that trustworthiness which covers credibility; transferability and dependability are significantly associated with reliability and validity within this research tradition. Research is said to achieve rigour if the appropriate research tools were applied during and throughout the inquiry so as to meet the stated aim of the investigation. In this study, the researcher was able to answer her research question with evidence to support the data (direct quotes from participants), by the use of suitable research method - IPA.

Creditability

This refers to the truth, value or believability of the findings through prolonged engagement with the data. The fundamental concept of the phenomenological approach is that there are many meanings of the phenomenon under investigation. Therefore to enhance creditability in qualitative research, Moules (2002) suggests

that the text should be offered to other readers who can open the interpretation further. Creditability had been ensured in this study by discussing the study findings and interpretations with the supervisory team who agreed with the interpretation as well as gave their feedback and comments, which were all taken into consideration.

Transferability

This is also referred to as applicability (Seale, 1999), and depends on the extent of how similar two contexts or circumstances may be. The original context should be appropriately illustrated and depicted so that the reader can make their judgment of transferability. Readers should be provided with sufficient contextual information to make similar judgements possible by others (Koch, 2006). Transferability has been ensured in this study by providing readers with full and clear descriptions of the social context of the participants so that they have a sense of their life experiences and can thus make a comparison. Moreover, themes from the analysis section are supported by direct quotes from the participants' interviews.

Dependability

This term closely corresponds with the concept 'reliability' in quantitative research (Golafshani, 2003), which suggests that results of the study can be replicated in identical conditions. The distinctiveness of the hermeneutic phenomenology is about the engagement of the researcher with the data which makes interpretation unique. Choosing the hermeneutic approach was not to generalise the findings of this study to defined populations, rather it was to understand the meaning of involuntary childlessness from Black African women in the UK. These meanings could vary between different women, and the variety of meanings would enrich our understanding of the phenomenon.

4.8 Summary

This chapter has presented the methodology and research design used to answer the research question and in doing so has identified the relevance of phenomenology and IPA specifically over other qualitative methodologies, like Grounded Theory and ethnography. It has also presented the details of the research design used to answer the research question and meet the objective of the study.

Chapter Five: Analysis and Findings

5.1 Introduction

This chapter presents the analysis and findings from the study. The analysis and presentation of findings draws on the guidance provide by Smith *et al*, (2009) for IPA studies. Following this structure the chapter starts with a descriptive summary of the participants, a presentation of the superordinate and sub-themes which emerged from the narratives, and then a presentation and discussion of the themes and sub-themes using extracts from women's narratives. The analysis and findings of this research focus on capturing and presenting the core individualistic experiences and perceptions of involuntary childlessness of Black African women while also preserving the idiographic nature of IPA.

5.2 The participants' descriptive summary

Table 5.1 presents an overview of the participants' demographic characteristics, followed by brief summaries of each participant giving the reader an idea of who the participants are. These summaries are not part of the data analysis but they only add transparency and essential element to the research. TTC stands for 'trying to conceive' and length of time of TTC are all based on the time of the interview.

Table 5.1 Demographics of involuntarily childless women

Name (Pseudonym)	Age	Country of origin	Religion	Level of education	Employment status	Years of trying to conceive
Theresa	30	Nigeria	Christianity	Tertiary	Paid job	2.5
Mary	43	Kenya	Christianity	Secondary	Paid job	5
Blessing	42	Nigeria	Christianity	Tertiary	Not working	7
Alexia	36	Nigeria	Christianity	Tertiary	Paid job	6
Christy	34	Nigeria	Christianity	Tertiary	Paid job	4
Precious	38	Nigeria	Christianity	Tertiary	Self- employed	12
Martha	37	Nigeria	Christianity	Tertiary	Paid job	5
Naomi	44	Nigeria	Christianity	Tertiary	Paid job	7

Theresa, 30 years old (TTC 2.5 years)

Theresa married over two years ago and had not been able to conceive at all. Due to her family's strong Christian values, she avoided pregnancy before marriage. Initially, she thought she will take a year off after marrying to settle down as she had only just arrived in the UK then. After a few months into her marriage, Theresa realised she was not getting pregnant even though she was not using any contraceptive pills and was having regular sexual intercourse with her husband. She is currently on the NHS fertility treatment waiting list after being diagnosed with multiple fibroids.

Mary, 43 years old (TTC 5 years)

Mary is already in her second marriage as the first one was dissolved as a result of involuntary childlessness. Her second husband has two children already with another person thus not putting any pressure on Mary for more children. After the divorce of her first marriage, she said she will only marry a man who already has children or

does not want any children. Mary is not having any fertility treatment at the time of this interview as she said if she happens to conceive naturally that will be great, else she will not bother too much.

Blessing, 42 years old (TTC 7 years)

Blessing recently joined her husband in the UK. She has been trying to conceive for seven years unsuccessfully. Back in her home country, she has undergone some basic tests and investigations which found nothing in particular to be the cause of her involuntary childlessness therefore she is classed as having ‘unexplained infertility’. Blessing is not currently having any fertility treatment as she believes that she does not really need ART to conceive but will rather wait on God for a miracle of natural conception despite being in her 40s where the natural conception rate is quite low.

Alexia, 36 years old (TTC 6 years)

Alexia has been married and trying to conceive for six years without any success. As she married as a virgin, the thought of ever encountering problems with conception was the least to have ever crossed her mind. However, that was not to be. All the medical tests and investigations she has undergone revealed nothing in particular to be the cause of her inability to conceive hence; she is classed as having an ‘unexplained infertility’. She has an open mind about assisted reproductive treatment and is currently on the NHS fertility treatment waiting list.

Christy, 34 years old (TTC 4 years)

Christy has been married and trying to conceive for four years without any success. She has also undergone a series of fertility tests and investigations, and she is diagnosed with ‘unexplained infertility’. She seems a free spirited woman who carries on with her life without being weighed down with the problem of involuntary childlessness. She is undergoing treatment on the NHS at the time of this interview.

Precious, 38 years (TTC 12 years)

Precious is the participant who has been trying to conceive the longest (12 years) with no success. However, during their medical tests and examinations, her husband was found to have a low sperm count which is one of the major causes of male infertility. She is still trying to conceive naturally. Her interview was the shortest and she also did not want her interview to be audio recorded but was happy for the

researcher to take notes of her narrative as she spoke deeply about her experience. Thus, it was manually written down on the researcher's fieldwork diary.

Martha, 37 years (TTC 5 years)

Martha has not recorded any successful pregnancy or even conception for over five years in her marriage. She had undergone several fertility tests and investigations which have revealed nothing significant about her inability to conceive. Therefore Martha is in the category of women with 'unexplained infertility'. Her gynaecologist has placed her on ovulation stimulation medication (Clomid) to see if that will help her conceive.

Naomi, 44 years (TTC 7 years)

Naomi has been married and trying to conceive for seven years without much success. After suffering a miscarriage four years ago, she has not been able to conceive again. Her case was initially down to a fertility issue with her husband who had to undergo surgery to try to correct it. Unfortunately, Naomi developed fibroids and had to get them removed. This now made her case more complicated. She is however not eligible for the NHS assisted reproductive treatment due to her age and cannot also afford the expensive cost of private IVF treatment. Naomi is in a dilemma now regarding fertility treatment while trying to conceive naturally as she is in almost her mid-forties.

5.3 Introduction of themes

Twelve subthemes emerged from the IPA analysis of the involuntarily childless women's interviews. They were organised into three superordinate themes: 'the vulnerable self', 'self and the social world', and 'coping with involuntary childlessness'. The three superordinate themes demonstrate common links and patterns within their corresponding subthemes. The subthemes are presented with direct quotations from the interview transcripts illustrating the participants' experiences in their own words. Following each quotation is the name (pseudonym) of the participant, page and line number where quotes were taken from. Descriptions and interpretations of superordinate themes and subthemes are discussed while also paying attention to variations in the participants' shared experience of involuntary childlessness or infertility. Table 5.2 presents the three superordinate themes and their subthemes.

Table 5.2 Superordinate and sub-themes

Superordinate theme	Sub-theme
The vulnerable self	<ul style="list-style-type: none">• Body image• Importance of motherhood• Coping with feelings• Self in the public domain• Helpless!
Self and the social world	<ul style="list-style-type: none">• Pressure of involuntary childlessness• ‘I’m pregnant!’ – Dealing with pregnancy news• Social judgment• Shame and stigma• Disclosure and exposure• Public perception of childlessness
Coping with involuntary childlessness	<ul style="list-style-type: none">• Trying to stay ‘sane’• Support and encouragement

5.3.1 Superordinate theme one: the vulnerable self

The participants in this study talked about their expectation and that of others particularly expressing their desire to start their own family. During the narratives, there was clear indication that plans to have children was a major part of the participants’ desired goal as married couple, yet when faced with the challenge of biological childlessness, they felt vulnerable to the prying eyes of both family and non-family members. As Precious was recounting her unpleasant experience about the way she was humiliated by her sister-in-law, she paused and said in a low soft voice;

“...but now my situation has made me vulnerable and people are now judging me but I know I am better off...” (Precious; Page 3, Line 94-96).

This echoes the voice of other participants who had felt vulnerable when asked questions by different people about having children and the reason they weren't having any. Theresa sums it up when she said,

“Even people you are not close to, they just want to know...that’s the most annoying part...they just want to make you depressed and all...” (Theresa; Page 5, Line 114 – 115).

While the desire to conceive and bear children was held by all the participants, what emerged from the data and is discussed below is the uniqueness of their journey to achieve their desired goal. Some women found the whole journey a bit bearable while some did not have the best experience because of how involuntary childlessness impacts on their relationships with their spouse, family and in-laws.

Some women described how the most private matters were made open for discussion by those who in the real sense should not normally be involved in it. As the desire for children is not only held by the infertile or involuntarily childless couples alone but also by their family, it made it even more difficult to keep certain matters private as they should be, such as when Alexia described her experience with her mother who became really bothered about her daughter's involuntary childlessness that she went 'overboard' when she asked Alexia,

“What is happening? Ermmm...is your husband...does he know how to make love?”(Alexia; Page, 4 Line 112).

There were narratives that described the state of questioning selves in utter disbelief of the situation these women found themselves and thereby felt helpless and vulnerable. Five subthemes are discussed below, and though they are presented independently, there are overlaps between these subthemes with an all-encompassing theme of the *vulnerable self* touching all throughout.

Body image

Some women's narrative seems to reveal that living as an involuntarily childless woman evokes unnecessary attention to the way they look or are 'supposed' to look in their appearance. Theresa described this aspect with annoyance and conveyed a sense of being judged by people because of looking the way she was with regards to her body size:

“Someone said, ‘you are fat when you are having a baby, you haven’t had a baby and you are this big” (Theresa; Page 6, Line 136 – 137).

Being involuntarily childless puts strain on women to put extra effort into how they present themselves to others regarding their physical appearance as the least sign of a bloated tummy can easily spark up speculations which might make the woman unnecessarily uncomfortable when it is noticed by another person. Naomi, who had fibroids which made her tummy always look big and bloated like a pregnant woman, said,

“I had fibroid obviously, that made my stomach bloat, so people make comments people are like, you know, my mother-in-law before she died [...] anytime I went to visit, she was just staring at my stomach, and I can read her expression like even though she was one of the rare women, she wasn’t battering me she wouldn’t poke at me she would only pray for me [...] but I will catch her out of the corner of my eye, I will see her looking at my stomach...” (Naomi; Page 10 Line 257 – 263).

Importance of motherhood

This subtheme reveals how Black Africans attach important value to motherhood such that the impact of not attaining that status is deeply felt by those who are involuntarily childless. All the women in the study at some point described how important it was for them to be a mother by having their own biological children. As motherhood is central to womanhood in Black African cultures, it was not surprising when some women described their unpleasant experience, as in the case of Mary who eventually had to leave her marriage due to involuntary childlessness:

“I can’t put up with this...it’s either you stay here and be made to feel horrible, miserable for the rest of your life [...] because of the pressure I was being put through....yeah....so my way of dealing with it was wanting to get out of the marriage”(Mary; Page 3; Line 87 – 88).

Participants expressed strong desire when discussing the need to conceive and experience motherhood. This desire was tied to socio-cultural expectations surrounding conjugal relationships but was equally expressed as an innate longing that could not be ignored. In the process of describing their involuntary childlessness

experiences, the participants explained how the desire for a child was often overwhelming, just as Alexia expressed it:

It is important [...] I mean how can I be full of so many good things and there is nobody to share it with....that kind of thing...ah there is someone you just want to pass on all you know....just help to see another little person like you and help the person become successful...you know...it is really important for me to see like how does it feel to be a parent...” (Alexia; Page 10, Line 307 – 310).

Motherhood is socio-culturally structured for a Black African woman; the benefits of having children have been spelt out since childhood:

“when I was a child because in Africa...in our community...when you are being raised [...] normally your mum and your dad [...]. they start mentioning from the age of 12..... ‘Oh when you get married’... ‘When you have children’...so motherhood is being thrown at us at little age....and the value of children are being thrown at you.... ‘when you have children, your children will do this for you’ [...] it’s instilled in you that as you grow older you will be a mom, so getting into marriage and all that...the first thing that comes to you is procreation” (Martha; Page 4, Line 121 – 133).

Coincidentally, all the participants were Christians whose belief of fulfilling the desire for motherhood is also seen as a mandate from God and, therefore, must be accomplished. Blessing expressed:

“Oh it’s the desire of every woman...even the Bible supports it that ‘you are a joyful mother of children and they will be round about your table and all that’...It is a joy... It is something that God has put...God did not create any woman to be without a child because He said, “go and be fruitful” (Blessing; Page 12, Line 384 – 387).

Furthermore, in describing the importance of children and being a mother, some women mentioned that the very essence of marriage in a traditional Black African society was for procreation and, therefore, having to leave one’s parents and be married to a man means children must ensue.

“In certain situation in Africa what do you do? [...] if you leave your parents’ house to a man’s house, if you didn’t want to marry why did you leave in the first instance, you have to stay with your parents but the purpose for marriage is for procreation isn’t it?” (Precious; Page 2, Line 45-48)

While all the women desired to bear a child and become mothers, it was interesting to hear Naomi asked if ‘only birthmothers were classed as mother?’ This was a bit of a debatable question as Naomi felt that non-birth mothers could equally take up the role of motherhood and in most cases, even do better as mothers than some birth mothers: she said,

“Because is it every woman who gives birth to children that you can actually call a mother? [...] No, in my own opinion no...Some women out there they find it easy to give birth but when it comes to mothering children...even one that has not given birth can do a better job...” (Naomi; Page 8, Line 221 – 224).

For most participants, the journey to motherhood and overcoming involuntarily childlessness will not be ended anytime soon till they achieve their desire of being a mother because of the value placed on the status of motherhood in Black African societies.

Coping with feelings

The constant struggle of trying to conceive brings the continual build-up of all sorts of feelings and emotions of sadness, loss, pain, frustration, tears, mourning and grieving as each monthly menstrual cycle passes with no sign of pregnancy. For Theresa, she had built up these emotions for a long while because she was not ready to accept that she was having problems conceiving a pregnancy, this led her not to allow herself to break down until after several unsuccessful months of no conception of pregnancy: she expressed,

“...at first am like oh God why me? Why me now? Does it have to be me? [...] cos the last time I even spoke to my lawyer and it was like flood gate of ...the tears I was holding back ... I just let it flow [...]. Then every night I realised that I hardly sleep...I just close my eyes and then I hear myself talking in

prayers ...I've tried to do fasting but because of ulcer I can't" (Theresa; Page 10, Line 245 – 263).

This was always particularly traumatic for Precious whereby every monthly cycle of no pregnancy was heart- breaking for her and all she did was cry during such periods. She lamented;

"...and then whenever you see your menstruation all you do is to cry...I tell you, it's not something you even wish your enemy" (Precious; Page 1, Line 13-15).

The emotional torment of seeing the unsuccessful cycle was nothing to be compared to the unsupportive attitude displayed by Precious's husband when she was made to leave her matrimonial home which resulted in a major emotional meltdown as she narrated

"...one night my husband started behaving as if he is mad...opened the window and started throwing my loads outside [...] I knoelt down in the living room, pulled my cloths away and became naked and say, 'I have married he because I love you, I don't creat children but because you are sending me away because I have no children, you will not hear the cry of a baby till I come back'" (Precious; Line 53-59).

The experience of childlessness made others question themselves as women who were not able to do what they felt was naturally expected of them. For some, it wasn't just the fact that other women could get pregnant, but the ease; and for some, there are those considered as 'not fit for a pregnancy' because of their state of mental health but were still able to easily conceive a pregnancy, as Alexia expressed,

"I just felt like 'why can't I like every other woman, even mad people get pregnant without effort' [...] so why can't I get pregnant easily without all these chaos and all these scientific things...you know..." (Alexia; Page 6, Line 190 – 194).

Also, similarly, Alexia also expressed her feelings of being treated as less human during her hospital investigation and treatment. She described her experience with the doctor as being treated as another 'piece of meat' while waiting in the hospital queue to be seen by the doctor. She said,

“...sometimes I felt embarrassed you know....sometimes the doctors themselves having to see so many patients during the day, they are not quite sensitive like you are another piece of meat, ‘let’s get this over with’ kind of treatment...you know” (Alexia; Page 6, Line 194 – 197).

Fear of the *unknown* was also seen as a disadvantage as much as it may be an advantage. Being diagnosed with ‘unexplained infertility’ could be a sign of great relief that nothing damaging has happened to the reproductive system as most of the participants described during the interviews. Most of the women said nothing was found to be the cause of their inability to achieve a pregnancy, and, therefore, they were happy in a sense that nothing medically was found to be wrong with them. However, there was that big ambiguous question, ‘why can I not get pregnant’ left unanswered, as Christy described,

“Emotionally...it makes you ask questions ... you ask questions definitely ... it’s even worse when you are told everything is ok ... and ermmm ... and then you are wondering where next?” (Christy; Page 7, Line 222 – 225).

Self in the public domain

Being out in public places was a challenge to most of the women as they feared public confrontation and scrutiny of their childless state. Not only did the women experience such confrontations but there is a sense that some of the women greatly disliked the manner and approach of the way these ‘verbal poking’ into their personal affair were tossed about casually and insensitively by others:

“...and every day I walk into the store...2 or 3 days ago, he reminded me ... I am giving you morning shifts ...cos he said to me, “if I give you evening, how do I expect you to have children, now I’m giving you morning shifts try and” [...]. [...] he’s comparing me with my colleagues [...]. She’s five years married, and she’s not trying [...] and he’s comparing me with her ... sometimes I just feel like saying to him, “shut up!” (Theresa; Page 14, Line 346 – 358).

Not only did some women describe the embarrassment they felt when faced with such intruding questions by members of the public, but they also expressed how difficult it was for them to hide away from certain places that may give away

information about their fertility struggle. Alexia, for instance, described that it was difficult to hide away from certain sections in the hospital such as those that carry the sign ‘*fertility clinic*’; which is not difficult to decipher that it is a special clinic for those who have problems conceiving. As infertility is widely viewed and experienced as a stigma, it then follows that those who themselves are involuntarily childless would make conscious effort to avoid places that will raise *eyebrows* in suspicion even though hiding away was quite difficult in practice:

“...and most times you come, you have to wait and then when you wait at a certain section of the hospital, people know why you are there, and they are looking at you [...] already there is a stigma [...] it’s written there, you know...you are sitting in that section...that kind of look, you know, but you just get on with everything...” (Alexia; Page 8, Line 245 – 251).

There is a sense from the interview that when in a Black African gathering as an involuntarily childless woman, there are certain discussions that will suggest the non-acknowledgment of her intellectual contribution especially when the discussion borders around children:

“...and then you are in a meeting where there is a talk on parenting, you are not expected to chip in because you have not got any experience [...] I kind of find it strange because [...] if you go to churches where you have predominately White people, even young people who are not married could get up and talk about that but sometimes in the African settings [...] they will be like ‘what do you know, wait until you have yours’ kind of...” (Christy; Page 13, Line 404 – 411).

Not only is their contribution to the discussion about children as childless women are often being disregarded but also the urge some people feel to express unnecessary pity over their state of childlessness which some women may deem embarrassing and uncomfortable when displayed publicly in the midst of others. Christy did not find such gestures particularly pleasant:

“... the other day, just speaking to a man about something...with the children department [...] immediately I just said children, someone walked up to me saying ‘I have a word for you’ am like it’s not the time [...] cos I don’t like

this thing of [...] when you are talking about children, then everyone who is around you knows “oh am encouraging her”. You can encourage me with this privately [...] you don’t have to do it like [...] it’s a problem” (Christy; Page 9, Line 291 – 299).

However, contrary to feeling in a certain kind of uneasy way like most women described, Martha felt that as involuntary childlessness is a very sensitive issue, her friends and the people she came in contact with respected her personal space and position and thereby avoided talking to her about it which was good for her:

“...what we do when we are outside [...] people don’t even know that I don’t have any [...]. I have good friends around; they don’t pressure me [...]. I think because it’s a very sensitive issue [...] they don’t want to talk about it as we [...] they respect the position that I am in [...] it’s working out for me so far [...]” (Martha; Page 4, Line 146 – 161).

Helpless!

As a result of involuntary childlessness regularly steering feelings of helplessness, exploration of the transcripts revealed that for some women, that meant relying only on what the specialists would recommend or even do for them. For Alexia, such reliance felt like a ‘gambling game’ where winning is not guaranteed: she said,

“I felt helpless [...] I felt frightened [...] because everything they tell you had a side effect [...] and you never know and it’s not a guaranteed situation [...] it’s like let’s try kind of situation [...] and you are always like ‘will it happen, will it not happen’ [...] you are like helpless, you can’t help yourself, you just need those people to just come up with whatever expertise you know can help you kind of thing [...] it’s really a hopeless situation to be really [...]” (Alexia; Page 9, Line 293 – 298).

Going beyond the sphere of holding onto the slightest glimpse of hope, that the seemingly unguaranteed fertility procedure or treatment offered will bring the much-desired news of pregnancy, there were also narratives that the expectation from others to get pregnant *soon* seems quite difficult to cope with. For Theresa, there is a sense that she was particularly apprehensive about the way her workplace colleagues put extra strain on her because she did not disclose her pregnancy struggle to them.

She discussed how she felt like disclosing her pregnancy struggle to her manager who seemed to use the least opportunity to tell her to get pregnant, so as to help reduce the pressure on her:

“... they keep saying to me at work [...] when are you [...] my manager [...] is like am going to strangle him one day (laughing) [...] he’s like, “when are you going to have a baby? [...] Am like soon [...] and then someone else have been pushing [...] you better have a baby that she’s now pregnant [...] and am like [...] omg [...] the whole store is pregnant!” (Theresa; Page 14, Line 339 – 343).

During the interview with Mary, there was a sense that though with a good level of education, her former husband did not seem to understand that Mary’s inability to conceive was completely out of her control, and she needed his understanding rather than joining the popular Black African *bandwagon* of assuming that infertility is the fault of the woman in a relationship, as she illustrated:

Why would I want this on me? [...] so the person whom I married, even though he was educated [...] but the fact [...] the mentality was [...] you know [...] I could see where the mentality was going [...]. So I thought to myself [...] erhhh [...] am not waiting for this to get to that [...] you know [...] am not waiting for this to get that far” (Mary, Page 5, Line 136 – 139).

Though Mary was already under intense pressure from her parents-in-law to bear children, she expected her husband to be sensible enough to support her during this particularly challenging period in her life. Moreover, Mary thought that with a higher level of education, her former husband could be expected to be more rational with her. Similarly, Precious talks of how she even developed a sleeping problem and could no longer perform well in her studies during her teachers’ training programme as a result of her separation from her husband. This separation caused her grades in college to be poor, and she was compelled to disclose her problem to her lecturer who then provided a sort of support to her.

5.3.2 Self and the social world

As an almost daily encounter in their lives, most of the participants talked about their experience of involuntary childlessness both within and outside their family. The women all highlighted such a point in their life where they had to deal with pressure, scrutiny, criticism, stigma, shame, social judgement and many other unpleasant encounters while trying to live a *supposed* normal life. The six subthemes discussed below highlight the kind of difficulty and personal struggles of the participants' experience of involuntary childlessness.

For some, being unable to get pregnant and bear children was seen as a private matter and they made effort to keep the information about their reproductive failure away from others. However, the participants spoke about their struggles on deciding whether to disclose their reproductive problem to others or not, in order to reduce the social stigma they were experiencing. The perception of infertility in Black African societies as being rather stigmatising and shameful seemed to influence the way these women interacted with family and society at large.

Pressure of involuntary childlessness

As earlier discussed in the subtheme 'importance of motherhood', the value placed on motherhood in a patriarchal society like a Black African one is immense. Thereby, it is not surprising when those who are faced with the difficulty of attaining that status of motherhood are under both internal (family) and external (society) pressure to bear children.

For Theresa, this challenge seemed to revolve around her immediate family. It was gathered that her mother, in particular, was not pressurising her in a negative way but was rather worried because of what she felt might be an issue with the in-laws. Theresa talks of her mother's worry and pressure to conceive as trying to protect her: she highlights,

"...after two months [...] the pressure from my parents was [...] After that I told my mum [...] she's like "oh it can't be" [...] the pressure [...] she's just worried about my in-laws I guess [...] she's not worried like she doesn't have grandchildren [...] I'm sure she's worried because one day my in-laws will

ask and my father-in-law [...] he has so much faith in me [...] I think that's what she's trying to protect ..." (Theresa; Page 10, Line 251 – 256).

While the pressure experienced by Theresa was born out of motherly love and concern, the same cannot be said about the kind of humiliating type of pressure Mary and Naomi experienced as previously illustrated in the subtheme 'helpless'. Mary's experience of pressure from her mother-in-law was made even more unpleasant when she openly made a suggestion to Mary's husband that he should marry a woman in a professional career because she perceives that women in nursing and teaching careers are more likely to bear children:

"...there was a demand [...]. 'When are you going to have a child?' [...] you know, I would be there and my mother-in-law will say, "Oh please marry this one, this one is a teacher, this one is a nurse, this one [...] that one can have children [...]" Ahhh [...] I'm like seriously?" (Mary; Page 3, Line 78 – 80).

"...my father-in-law on the other hand is one that you know was quite nasty to me [...] I did feel pressurised [...] and that marred my relation with my husband ..." (Naomi; Page 10, Line 269 – 271).

Some women described the social pressure and demand placed on Black African women to start bearing children immediately after marriage as described by Precious and Alexia;

"I have been living with my husband, but the pressure of his people became so much. You know Africans now, soon as you are married they want a child immediately..." (Precious; Page 1, Line 9-10).

"It's typical of Africans you know [...] they expect you [...] nine months from the date of your wedding you need to have a baby..." (Alexia; Page 3, Line 95 – 96).

For Alexia and Christy, their experiences of pressure were quite similar in that both women are sisters who have been rather unfortunate to be involuntarily childless, resulting in an even added pressure not only on them but on their immediate family too. Intimate and private matters between couples are normally meant to be kept only between the people involved in the relationship but Christy and Alexia's story

highlighted that their mother was more involved in theirs by demanding details of rather personal information. Christy described her experience as ‘uncomfortable’, having to discuss such private and personal issues not only with her doctor but also with her mother: she narrates,

“It makes you uncomfortable [...] especially when they are asking you “when last did you [...]” “How often do you do it” [...] it makes you uncomfortable [...] you are going too far now [...] sometimes they kind of like want to know how frequent [...] I could be a private person, so for me it was kind of uncomfortable [...] you are trying to know too much [...] you are digging into our personal lives...” (Christy; Page 6, Line 177 – 183).

Alexia equally described similar experience that her mother even had to monitor and question every monthly cycle:

“...she was calling me like week after week [...]. “Have you seen your period?” [...]. ‘Yes I saw my period’ [...] She will start counting for me [...] so she was more like keeping track [...] “have you seen your period now cos from the last time I started counting it was” [...] it got to a point where I had to tell her I was no longer keeping track of my period [...] I had to tell her ‘no I can’t remember but I know my husband knows about it cos he’s very good at keeping dates’ [...] so it was kind of taken the pressure off me cos she couldn’t call him to ask [...] She will say ‘find out from him and let me know in the evening’...” (Alexia; Page 5, Line 128 – 141).

In most African societies, the pressure of involuntary childlessness is not only felt by the affected couples but seen as a problem indirectly affected by the immediate family especially the couple’s parents. Though Alexia and Christy’s mother was seen to be pushing her daughters’ personal boundaries, she was thought to be doing that not only out of love and concern but because of the social pressure she may have experienced from her peers who may have been asking her about grandchildren when out in social gatherings:

“I feel maybe because she also had pressure you know[...] she had pressure because many people had friends that had girls my age [...] got married [...] some got married before me, some got married the same time I got married,

some got married afterwards [...] so they were always having babies, and you know[...] it was like she wasn't telling the [...] you know, the African thing, she couldn't tell them she had babies [...] she had a grandchild" (Alexia; Page 5, Line 162 – 166).

'I'm pregnant!' – Dealing with pregnancy news

Considerable emphasis was placed on how other people's pregnancies impacted on the participants' day-to-day coping with involuntary childlessness. During the interviews, it was sensed that since pregnancy was such an important and visible part of reproductive success, other women's pregnancy, and the birth of a new baby within the family were difficult to bear. Not being able to get pregnant was made all more difficult by the fact that *everyone* else seemed to be pregnant. Theresa narrated her experience of being in utter shock when her colleague to whom she had disclosed her struggle with infertility, announced her pregnancy to her at an inappropriate time:

"My colleague [...] she knows about what I'm going through because most times I come to work depressed and [...] and then one day she came to work and [...] She was like, "[...] I have something to tell you" [...] I just finished telling her now that am going to do a surgery, and she's like oh it is well [...] she wanted to leave [...] then came back [...] "I'm pregnant!" [...] I just held the tray [...] I didn't know when I just screamed Yeah!!!" (Theresa; Page, 18, Line 465 – 481).

For some women, pregnancy was a visible signifier of what they were not able to achieve. There was a mixed feeling of despair and hope during the interview with Blessing as she described her longing to carry her own babies; saying it was only natural to feel that way, but nevertheless she will remain very hopeful for it to happen one day:

"...we are all human [...] you feel like, 'God' [...] 'I want to have my own', 'I want to hear the cry of a baby in my home', [...] it is a natural thing [...]. Once in a while [...] you'll just sit down and say, 'God [...] I just know that this will be over one day, I will surely carry my own babies in my arm' [...] so it's a natural thing that comes once in a while..." (Blessing; Page 8, Line 239 – 245).

The experience was a painful one in which Naomi had to make a conscious effort to be happy with the pregnant women she knew by suppressing her negative sentiments rather to react in a positive way towards the pregnant woman:

“I have to make a conscious effort to rejoice with them, but part of me still feel sad that what is it that [...] there are times I’m feeling like ‘have I done something wrong?’ [...] in fact, I had to like erm [...] make a conscious effort to fight my negative emotions, so when I see myself like feeling jealous or feeling down or anything, I do the exact opposite of what am feeling...”
(Naomi; Page 12, Line 326 – 332).

For Alexia and Christy, pregnancy news of others meant more pressure from their family. Coupled with their feelings of disappointment, they did not stop to ponder on the thought that a woman’s fertility is known to decline with age as well as thoughts of being an old mother:

“...definitely you are gonna be happy for them but that little feeling ‘how I wish kind of’, you know’ [...] ‘What is wrong with me kind of feeling’ [...] you feel bad and then for a while you are thinking [...] how many years have you got now, if I have a child now, when he’s 10 years how old will I be kind of thing...” (Alexia; Page 10, Line 365 – 368).

“...maybe because I’m an analytical person [...] sometimes you kind of think [...] you just race through your head ‘how old are you’ [...] hmmm [...] ‘Ok she had her baby at 36’ [...] hmmm ‘ok’ [...] ‘Yes it’s possible’ [...] you know, you are playing things in your head...and then when people talk about erm [...] once you are over 35, your chances are slim [...] are you like [...] you just keep calculating...” (Christy; Page 10, Line 324).

However, for Martha the pregnancy news of others did not make her feel sad, jealous, regretful or any negative emotions. She was happy for the pregnant women as she remained positive and hopeful for her own pregnancy to happen one day:

“I’m happy for them [...] when I come home I share with my husband [...] if my husband hears it first he shares with me [...] we are very happy for them [...] I don’t feel regret of [...] or why it won’t be [...] because I know my time will come...” (Martha; Page 5, Line 181 – 184).

These findings demonstrate the distress that pregnancy news held for women in their day-to-day lives as involuntarily childless women. In many cases, despite being in emotional distress, the women were in fact very happy with the news of others' pregnancy.

Social judgment

The lack of physically showing the result of successful reproduction in the form of either pregnancy or biological children meant having to encounter different forms of social stigma about childlessness from people at all times and at different places. Most participants described the ways in which they had to deal with insensitive remarks, comments and attitude regarding their involuntary childlessness and most of the time, they were quite hurtful.

In the past few years, social media platforms such as Facebook, Whatsapp, Instagram etc. have broadened horizons, making it even easier for many people to have access to connect with people without having any physical contact with them. It has been a recent trend that many people take to these platforms to announce all kinds of news or information they want to share with the public, pregnancy and baby news being among such announcements. Theresa described how she had to stop going on Facebook because people she knew were asking why she is not having children, which she found rather difficult to deal with:

"I stopped going to Facebook because every time I opened Facebook [...] babies [...] then having to face people asking me stupid questions like, "when are you having a baby?" [...] someone was like, "you never wan (want) born?" I stopped talking to her [...] I just didn't reply her [...] there was no point replying her [...] and when she said it, I was so sad..." (Theresa; Page 4, Line 94 – 101).

Apart from the online social media pressure which one could easily get away from by avoiding logging into one's account, social gatherings of people such as going to church meetings, attending weddings, birthdays, funerals etc, creates opportunities for them to meet with many people including family and friends, who are most likely to ask about one's children. One of the participants highlighted how she was *told off* when she tried to offer help with other people's kids:

“... first of all, you are trying to help with changing a child who’s probably messed up [...] and then it’s more like erm [...] ‘abeg wait make we do am’ (please wait let’s do it) [...] that kind of thing...” (Christy; Page 13, Line 403 – 409).

Similarly, Alexia felt talked down to when she offered her opinion on parenting matters in a church meeting:

“Churches [...] yeah [...] meetings especially meetings where you’ve got Africans [...] you can tell a lot by how they treat you [...] maybe when other people are talking about their children and the challenges they are having with parenting ‘you, you don’t understand what we are talking don’t worry until when you have your child’ kind of talk...” (Alexia; Page 13 Line 405 – 408).

Social stigma does come in different forms and can cause the childless woman embarrassment and heartbreak. Naomi narrated how she was not allowed to buy some baby items from a car-boot sale by the seller who was quite insensitive to her because of her childless status:

“And people were buying stuff [...] you know, and I came also to pick a few things and she was like ‘what do you need them for?’ I said ha, for my own children too when they come [...] and she was like ‘they are not here yet, let those who have children buy their thing...” (Naomi; Page 10, Line 276 – 278).

Shame and stigma

In many cultures around the world, involuntarily childless women suffer a great deal of discrimination, stigma and isolation. People’s negative attitude was regularly cited as the most challenging social stigma they had to face which attracts shame, being one of the most painful emotional responses to deal with. Though these two factors may be felt together they are nonetheless quite hard to handle.

For some participants, the social and moral anxiety surrounding infertility led them to withdraw from social life to varying degrees. For others, the constant pressure and questioning of their inability to have children meant that they stopped attending social events like birthdays, and in some cases, discriminated outright against them

by not even getting an invitation to such events. Naomi, who highlighted this during her interview, said:

“... I wouldn’t go to social function [...] you know because people will be having birthdays for their children and stuffs they will invite everyone else but they won’t invite me [...] And they like ahh ‘sorry now’ [...] even though nobody will answer me, it’s obvious I don’t have any children to play at the field...” (Naomi; Page 11, Line 290 – 296).

Similarly, some women also described that stigma was greatly felt in some women-only group meetings where talks of parenting were addressed. Alexia narrated how some talk-session dynamics was being skewed towards women with children:

“...especially when its women’s event [...] and they are talking about children, ‘ermmm you don’t really understand because you don’t have one’ kind of talk [...] or when they are addressing parenting issues, [...] you know you can actually see this segregation, they address some people with children...” (Alexia; Page 13, Line 400 – 403).

Furthermore, *barren* is a term commonly used in most Black African churches when referring to infertile or involuntarily childless women. However, to call any woman barren can be quite stigmatising because in such settings, involuntary childlessness are perceived to be more of a spiritual problem. Christy described that barrenness is such a heavy word that she cannot accept it:

“Childlessness, well like in the African setting it’s considered a spiritual thing, a spiritual problem, ermmm, [...] it’s stigmatising [...] especially when the word ‘barren’ is used [...]. ‘It’s heavy’ even like when you go to African church you know, so it’s just one of those things [...] it’s not a nice word, and I don’t accept those...” (Christy; Page 8 Line 254 – 260).

Particularly intriguing was Mary’s experience of shame and stigma with her mother-in-law. The effort not to disclose her struggle with childlessness was on several occasions forfeited by her mother in-law. This and others must have contributed to Mary’s decision to leave her marriage. She described that her mother-in-law would normally introduce her to outsiders as an infertile woman:

“... my mother-in-law, I don’t know if she was mad or what, because she will meet people and she will say, “Oh this is my daughter-in-law, she’s been married for this amount of time, and she doesn’t have a child [...]”. That’s how she will introduce me, and her husband [...] he would say [...] I was eating food for nothing because I couldn’t have children” (Mary; Page 11, Line 331- 343).

Disclosure and exposure

Assisted reproductive technology (ART), which has gained massive popularity worldwide in recent years, is still viewed sceptically among some people from Black African communities who do not understand much about ART. As infertility is seen to be socially and culturally stigmatising, disclosing the use of ART to others may prove problematic. Women are confronted with the decision of issue of whether or not to disclose their reproductive failure to people. There were quite mixed opinions among the participants during the interviews regarding who they would likely disclose their infertility struggle or diagnosis to.

To some women, stigma was mentioned as the main reason they will not discuss their problem of conceiving pregnancy with any other person apart from very few close family members. Name calling was particularly an obvious reason: Blessing said she would not disclose, implying that those women who may use ART would be looked upon as not being capable of achieving what other women could easily achieve:

“You know, there is nothing wrong in disclosing it you know [...] the Blacks [...] they may take it up and say, ‘ah, that one, her womb is weak’, ‘her womb is not strong’, [...]. Some they will say, it’s not really natural [...] she has not really passed through womanhood [...] I think that’s the mentality...” (Blessing; Page 10, Line 322 – 328).

Pregnancy is believed to be an immediate and natural result of marriage in a Black African culture, therefore; the absence of pregnancy and children raises concern of interference by others. A few participants expressed how it was easier for them to disclose their infertility challenge to people who they were not close to. Theresa made the decision to confide in a work colleague because she found it easier to talk to an outsider about it:

“You know it’s easier to tell people that you don’t know that you are not so close to [...]. I somehow told my colleague, but she doesn’t know the full story, I just gave her like just a little [...]. Like immediately I left the clinic, I called them and they like, “this is the plan, you won’t tell your parents-in-law, and you would tell your husband [...]” and then I told my sister-in-law...” Theresa; Page 7, Line 151 – 159).

On the other hand, Martha who came across as a very reserved person during her narrative was not happy to disclose her fertility struggle with anyone else apart from her husband because she felt it was too sensitive an issue to disclose to people:

“Nobody, it’s just I and my husband really, because it’s something I don’t discuss with anybody really [...] even people who would have wanted to, don’t go there during conversation because it’s a very sensitive issue so even if they would love to. They don’t go there, the only person that I would have told is my mum but she is not here anymore ” (Martha; Page 6, Line 188 – 192).

Disclosure of infertility or the use of ART to other people seemed to be an issue to most participants. Some maintained that disclosure could only be to those in similar situation just to encourage and support a fellow involuntarily childless woman:

“...because we run a ministry, and I have to encourage someone who is probably considering going for the process...yeah I might have to help that person...build faith and what God can do through medicine ...” (Christy; Page 7, Line 217 – 219).

For Naomi, she made it clear that if she was to use ART to conceive a baby, such disclosure will only occur after a successful treatment which brings home a baby:

“...definitely, the only thing is, I would want it to be like ermmm, I will have my chil, then I will say ‘yes, we did IVF’, yeah they need to know because people need to change their attitude ...” (Naomi; Page 7, Line 189 – 191).

Public perception of childlessness

In certain societies in Black Africa, infertility and involuntary childlessness have been attributed to an act of God, punishment for a past promiscuous lifestyle and

even more commonly, the result of witchcraft. The women's accounts during the interview revealed existing attitudes and beliefs about childlessness. There is also a strong belief that the solution to childlessness must be sought from God even though most people do not dispute the ability of medical sciences.

Theresa had a friend who was equally struggling with infertility though was fortunate to conceive a pregnancy along the line, but then turned around to tell Theresa that she needed to go to a 'living' church and pray, implying that Theresa's problem was more spiritual than medical and thus must be earnestly guarded against:

"... cos when I said to her I went for HSG, this is the result, she's like, "what church do you go?" I was angry [...]. The first thing she said to me is, "do you go to a living church?" I wish she could see my reaction [...]. I was just weak [...]. I now said to her, 'Yes', 'Why?' [...]. "Ermmm you need to pray, God forbid you need to pray" ... (Theresa; Page 20, Line 503 – 510).

Moreover, being religious and attributing the inability to bear a child to be a result of witchcraft was only one thing about people's attitude towards childlessness, but having an often generalised perception that certain lifestyles (like promiscuity) and women's exposure to attending higher education institutions, were frequently cited to be another cause of childlessness as described by some participants:

"... I heard quite a lot, [...] ermmm some people were because of lifestyle, maybe during their young teenage age stories I heard from them, they were unable to conceive, at least, to those people there was a reason..." (Alexia; Page 10, Line 320 – 324).

"...you know people think if you don't have children in Africa, you are a condemned woman, you are good for nothing [...] they will say 'where is this one coming from? She has gone and educated herself when she was educating herself, she has aborted all her pregnancy'" (Precious; Page 3, Line 90-92).

"...there was one other woman, who had come in, and she was giving this generalisation like, "all of us have done various things when we were young", and I'm thinking, I didn't do anything with my womb, I didn't even

sleep around, and my husband is my first sexual partner...” (Naomi; Page 8, Line 200 – 203).

Perceptions and speculations that women who go to higher education institutions are free to live the kind of life that pleases them arise because it is believed that they are now adults and no longer live under the close monitoring and supervision of their parents or guardians. Thus, as a result, they are perceived to live a promiscuous life leading to unwanted pregnancies which are illegally terminated, and develop STDs which in some cases were not properly treated and may ultimately be the cause of their childlessness.

5.3.3 Coping with involuntary childlessness

It is normal and only natural for involuntarily childless individuals to feel a monumental sense of loss, despondent, frustrated and devastated when they are constantly faced with the pressure from their family and the community in which they live. All these feelings were expressed at some point by the participants during the interviews. However, the ability to go through all these emotions and still manage to stay ‘sane’ was an attitude these women developed through support from loved ones, engaging in activities such as their daily jobs; and most of them being Christians said that they have faith in God to help them overcome their fertility problems.

Trying to stay ‘sane’

For some women, praying was cited most frequently to be their coping strategy:

“...so every night I just keep praying, talking to myself, I think now I’m able to stay sane. I just keep touching [referring to her tummy] praying in Jesus name” (Theresa; Page 13, Line 315 – 317).

“I’m a Christian, and the backbone of whatever I do is usually running to God, you could get into the place of prayer, cry, talk to God about it, so in the place of prayer, He reassures you, I mean that’s the way I’ve learnt to deal with things, I go to God in prayers, He assures you, get a word, then you can carry on again...” (Christy; Page 7, Line 228 – 231).

“I’m a Christian like I said [...] as a Christian if what you believe that, what you are praying for will come to you, you will just keep that faith, and

because I believe in God, I believe that God will answer my prayer, I didn't need to feel bad about it, that 'why it is taking so long?' we just feel in the right time, it will come..." (Martha; Page 3, Line 99 – 104).

While Blessing did more than just praying, by carrying out some spiritual activities in order to invoke the blessings of pregnancy. She was quite passionate about buying gift items for new born babies as 'sowing seed'; and also keeping some baby items in her possession as an indirect way of attracting the blessings that she believes come with the baby:

"...most of my baby things are in the house, I couldn't bring them her, we were instructed not to give it out, sorry this is a bit religious, I only brought some as a point of contact [...] personally, naturally that's what I do [...] because I am sowing a seed into the child [...] because that is a newborn [...] they don't talk but as you bless them, you know somehow they are speaking, but you may not know..." (Blessing; Page 8, Line 247 – 259).

However, for Naomi even though she also prays and has faith that God will bless her one day with a child, her major distraction and coping strategy was her job as a teacher where she had contact with other children; she described:

"I am teacher, I take classes, so I have to go on with my life so what I do is to put myself into lots and lots of activities you know, to try and take my mind off from what is going on..." (Naomi; Page 6, Line 142 – 148).

Support and encouragement

When a person is struggling with involuntary childlessness, and all effort to be pregnant is slashed away every passing month; or if they are fortunate enough to become pregnant, only to have it taken away almost immediately by miscarriage/stillbirth, they often turn to their loved ones for the hope of support and comfort. The narratives of the participants centred on the support and encouragement of their family and friends. Some described that the support which they had from their spouse helped them to cope better:

"My real succour is my husband really [...] my husband hasn't even gone there at all, you know, he's not even bothered [...] he's getting on with life as

life comes every day, we are just living our lives really...” (Martha; Page 5, Line 164 – 171).

“... ‘if we don’t have babies we are not going to die’, he said, I mean it’s not the end of the world [...]. “You know I’m getting married to you not because I wouldn’t love to have children but if we don’t have children, I mean that’s not what our marriage is all about”... ” (Alexia; Page 7, Line 210 – 216).

“My husband was not like the usual, you know, like the typical African men that you see around that once their wife cannot conceive or whatever, they just go off...” (Naomi; Page 6, Line 148 – 150).

Others spoke of the support of their parents and even in-laws as they did not pressurise them, but rather showed some understanding about their situation;

“My family have never put pressure on me, never I’m not the only one so it’s no pressure” (Mary; page 13, Line 413 – 417).

“I told them and they were like, “I should take my time [...]. Was like, “just take your time, don’t let someone disturb you” In fact, their dad was like, “any news let us know”, they are just cool ...” (Theresa; Page 7, Line 163 – 167).

“...for some people it is like hell. I must give God thanks in my own case, I’ve never had any form of stigmatisation whether from my siblings or from my in-law, nobody has that time [...]. Even my sister-in-law [...] they desire us to have but no one is coming to say ‘ha, how many years now? What is happening?’ No no no, I have a good flow with them” (Blessing; Page 12, Line 368 – 374).

5.4 Summary

This chapter presented a detailed IPA thematic analysis of the involuntarily childless Black women’s experiences of infertility. Three superordinate themes with twelve subthemes emerged during the data analysis as experiences shared by the participants in this study. Chapter six summarises the key findings of the study and discusses them in the context of existing literature on involuntary childlessness. It

also discusses suggestions for further research in this area before drawing conclusions.

Chapter Six: Discussion and conclusion

6.1 Introduction

This final chapter presents a discussion of the findings in relation to the research question and conceptual underpinnings on involuntary childlessness. It then turns its attention to the strength and limitations of the study and makes suggestions for future research. The contributions the study makes to the field are outlined before the chapter is concluded.

6.2 Findings and existing research

The previous chapter described the difficulty and often overwhelming experience of involuntary childlessness faced by the women in this study. The interpretative nature of IPA, especially the double hermeneutics used during the data analysis, allowed the researcher a good chance to plunge deeply into the ups and downs of the women's experiences; as well as what such experience meant to them individually and as a group. (Harris, 2012).

The research question asked was: what are Black women's experiences of involuntary childlessness or infertility in the UK? The hermeneutic approach of Martin Heidegger's *Being and Time* (1962/1927) was adopted. Upholding the integrity and maintaining rigour of this research, the researcher maintained a close relationship between the participant's original words or meaning and the researcher's interpretation of the data, which was done through repeated visits to the interview transcripts; thus achieving the primary aim of interpretative phenomenology. As earlier mentioned, this study does not propose to provide the *final word* on the experiences of involuntary childlessness (Smith and Eatough, 2007), rather it acknowledges that other researchers may have different interpretations while using the same research methods, and even the reader's interpretation may also slightly differ.

The key findings in light with the existing literature are discussed below. The three superordinate themes – 'the vulnerable self', 'self and the social world', and 'coping with involuntary childlessness', which are discussed here – sum all the individual subthemes from chapter five, and are important when considering the aim of the research. It is however recognised that there may be certain areas of the analysis

where the reader may be interested in further exploration. However, due to the word limit of this thesis, it is not possible to carry out detailed discussion of every theme.

6.2.1 The vulnerable self

Going through in great depth, the interview transcripts of the involuntarily childless women reflected the sense that the whole experience of trying to conceive and bear a child has not been particularly an easy one. Most of the women expressed their despair and helplessness as they poured out their feelings about not being able to be like *every other woman* who did not find it difficult to achieve pregnancy whenever they wanted. According to Inhorn (1994), bearing children is a high expectation of women especially from pronatalist societies to establish their adult identities, and in most developing countries the gendered consequences of involuntary childlessness can be grim.

Echoing the expression of Alexia “*why can't I be like every other woman, even mad women get pregnant without effort...*” (Page 6, Line 190 – 194), for the involuntarily childless woman, finding herself in a situation where it is absolutely out of her control or power to change that which causes her so much pain and anguish is what Atwood and Dobkin (1992) describe as the mourning and grieving process in infertility.

Originally listed by Afek (1987) as the *Eight Stages* of the grieving process experienced by the infertile women, Atwood and Dobkin (1992) later merged them into four stages: “(a) disbelief and denial, (b) anxiety, anger, and feeling of loss of control, (c) isolation, alienation, guilt, low self-esteem, grief and depression, and (d) resolution” (Atwood and Dobkin, 1992); and suggest that infertile couples generally follow similar pattern when mourning the loss of their loved ones.

As mentioned in chapter three, Peter and colleagues have reported that grief related to involuntary childlessness have been found to be on-going, but unlike the death of a loved one which is typically shared with friends and family, infertility related grief is not usually a public affair (Peter *et al.*, 2011). To further compound their feelings of loss, some women like Naomi and Precious in this study described their feelings of loss and grief as like revolving in cycles of becoming hopeful at some point, and then feel completely hopeless at another point, then back at being hopeful again every passing month when they have their menstruation. Atwood and Dobkin (1992)

mention in the second stage (anxiety, anger, and feeling of loss of control) of their four stages of the mourning and grieving process that such individuals may swiftly burst into tears when they are triggered by events that reminds them of their situation. The authors argue that this stage for most individuals is like an emotional *see-saw*, characterised mostly by psychological uncertainties (Atwood and Dobkin, 1992).

There are on-going arguments about the accuracy of conceptualising the psychological troubles observed among people with reproductive failures as psychiatric sickness or as an acute psychological response to an unusual personal situation (Fisher, 2009). For example, in a study of the psychosocial adjustment of infertility and its treatment, Beaureparie *et al.* (1994) found higher levels of clinically significant symptoms of depression and anxiety among their participants who were seeking fertility treatment. Similarly, Kerr *et al.* (1999) reported that over 20 per cent of women who were attending an infertility support group reported episodic suicidal ideation. Nevertheless, describing these conditions as psychiatric illness has been criticised, even though the psychiatric illness checklists also include somatic symptoms (for example, there is a problem with my body) which are regularly said by involuntarily childless or infertile women (Fisher, 2009).

There are scanty systematic studies that have explored the psychological effect of infertility in less developed societies, and little is known about the psychological functioning of women with reproductive failures in those places. Inhorn and Buss (1994) describe this situation as representing an Eurocentric concentration of many studies in this area. In a single study carried out in Nigeria by Aghanwa *et al.* (1999), the authors highlight that 29.7 per cent of women with reproductive failure suffered depression or anxiety disorder when compared with 2.7 per cent of women without reproductive problems in a controlled trial.

To have an understanding of the degree of importance of self-worth with regards to issues of involuntary childlessness in this community, social identity theory contends that a person's sense of worth depends on the the group they identify with. In other words, individuals are in constant comparison with their group members in order to assess their potentials (Letherby, 2002). In this study, Theresa expressed her displeasure towards her work manager's attitude of constantly asking her when she

will have a child like her other pregnant work colleagues. Her expression whilst narrating her experience during the interview did not mask her feelings of helplessness and frustration.

The experience of involuntary childlessness as expressed by the study participants not only challenges and threatens their sexuality as women (Cooper-Hilbert, 1998) but also make them question their sense of self-worth. This experience was particularly awful for Precious who had a hard time dealing with involuntary childlessness and her in-laws. This finding confirms what Kielmann (1998) states, that an infertile woman is also considered useless by her mother-in-law and sister-in-law because she has not gone through childbirth or labour pain. For these women bearing children and having a successful marriage is an important way for them to achieve an acceptable social status.

6.2.2 Self and the social world

The findings reveal how involuntarily childless women manage to sustain an image and identity which has been threatened by their inability to attain the normative social status of womanhood. It is no doubt known that the importance of parenthood, and the demand to produce children, is almost universal and therefore when one does not live up to this demand, it makes one an 'outsider', and those who cannot have children are in almost every culture considered as persons of *less value* than ones who have children (van Balen and Inhorn, 2002). Several findings highlight that in many societies of the less developed countries, achieving a full status as an adult woman, women must first become mothers (Bustfield, 1974; Gillespie, 1999, 2000; Letherby, 1999, 2002; Morell, 1994; Culley and Hudson, 2009; Greil *et al.*, 2009). The narratives of the women reveal that even the number of years or time spent in the UK did not impact significantly on their beliefs about motherhood as an important identifier of an African woman.

Inhorn (1996), argues that the impact of the psychological consequences of involuntary childlessness for women from patriarchal societies are anything if not significant. This study shows that coming from a highly pronatalist society which encourages reproduction, birth, and parenthood for *everyone* means failing to conform to age-long established norms comes with its consequences. Almost all the women expressed that pressure to conceive had started mounting within a couple of

months after marriage. Though Alexia's experience of pressure by her family and in-laws to bear children was expressed more out of love and support than abuse, it was not a very tasteful experience for women like Mary and Precious who suffered severe consequence of involuntary childlessness – emotional/psychological abuse and divorce/separation respectively.

For Mary and Precious, the pressure which was exerted by their in-laws was accompanied with threats that their husband should get another woman who would be able to bear children for the family. This finding is consistent with others (see Hudson, 2008; 2012; Katbamna, 2002; Inhorn, 1996; Culley and Hudson, 2009). In her case, Precious suffered the humiliation and shame of her husband getting another wife, which she had to give her consent to though she had no choice as the husband's family would still have gone ahead with the plans of marrying another wife for their son either way. Since she could not put up with the thoughts of living with a second wife, Precious had to leave her marriage and was very surprised to realise that after all these years, their problem was as a result of a male factor infertility because the new woman was not able to conceive and bear children as planned. Indeed male infertility is rarely acknowledged in many societies, particularly in patrilineal ones (Inhorn, 2003; Donkor and Sandall, 2007; Rashid, 2007).

Another theme that was frequently expressed by the study participants was the pregnancy of other women. The study findings reveal that it was always a mixture of sadness and joy for most women whenever the news of pregnancy was announced by their friends and family, and even more reason to question things. Women described that they were envious of others who announced their pregnancies. Kilbride (2003) and Harris and Daniluk (2010) described a similar narrative in their study of infertility where their study participants described that they were not able to be in the same company as other pregnant women and babies because it was quite distressing.

For Alexia, the pregnancy news always came as a shock to her. She said her heart sinks whenever another family member or friend announces a pregnancy because the next call coming through from her mother will put even more pressure on her than ever before, the reason being that Alexia's mother was equally facing the social pressure from peers during social gatherings. Such gatherings which are quite popular within Black African societies can be a source of happiness – for those who

have grandchildren to brag about, or sadness – for those women whose daughters are struggling with infertility. Inhorn (1996), in her groundbreaking text about infertility and patriarchy in Egypt, highlights the experience of one of her participants who said, “the pride of the wife’s family is also hurt because, maybe people will see that their daughter has something missing” (p.75).

Another theme that was striking in the study findings is *social judgment*. From the in-depth interviews, there was a sense that these women not only had their personal struggles with involuntary childlessness or infertility to deal with, but they also had to deal with the people they came in contact with in their daily activities which subsequently impacted on their psychological/mental well-being. Women in this study reported that they had to face people who were quite insensitive with their remarks and comments to them regarding childlessness. In a world that brings people so close to each other nowadays via the popular use of social media platforms such as Facebook, Whatsapp, Instagram etc, it is now very easy for people to display their personal achievements or accomplishments for many others to see, and one such is the numerous influx of weddings, baby showers and pictures of foetus sonograms and new babies.

Moreover, these social media platforms also create opportunity for people behind their computers and smartphones to taunt others. Such was the case with Theresa who said she had to stop going on Facebook because she was scared of the continuous questions about her involuntary childlessness she had to deal with. A blog writer for infertility and online support group Tessy Hoffman (2016) in her recent online post argues that the social media now makes every day seems like Mother’s day because access to social media platform brings the world closer to people, and involuntarily childless women can easily see and read endless posts about pregnancy and parenthood, and still feel jealous, sad, frustrated, distraught, devastated and grieved. Shapira (2010), a columnist for the *Washington Post* also notes that before the onset of Facebook, involuntarily childless women could consciously avoid pregnant work colleagues or pregnant women at social gatherings which will consequently limit their physical exposure to triggers of sadness and envy; but nowadays, people can feel trapped by numerous photos of friend’s pregnancies.

Apart from getting the jealousy pangs of seeing pictures of baby bumps and babies on social media websites, another challenge with the social world faced by the women in this study was the case of insensitive remarks and comments from those who were neither family nor friends. Kilbride (2003), who explored how involuntarily childless couples from Hull, Yorkshire communicate their fertility problem. Killbride highlighted that some participants in her study showed an awareness that other people who did not know about their fertility struggles would either make assumptions or comments that suggest they are better off without children because they can afford a good career and lots of pleasurable things of life (Kilbride, 2003).

Naomi's experience with a car boot seller was appalling – when the seller told her that she should allow those with children to buy because she has none yet. Some women reported that they were not really expected to give intellectual contribution during discussions about parenting in a Black African setting gathering, as Christy highlighted, *“then you are in a meeting where there is a talk on parenting, you are not expected to chip in because you have not got any experience”* (P13 L403 – 406).

Such discriminating attitudes towards the involuntarily childless women have been reported in an infertility study by Mogobe (2005) in Botswana. The author argued that in their daily lives, women socialise with their fellow women in their community where discussions of childbirth and motherhood are topical. During such discussions, involuntarily childless women would have nothing to contribute because their views and opinions are not valued as they have never experienced the pain of childbirth, and thus cannot possibly know any better which made them felt like outsiders in the midst of other women (Mogobe, 2005).

Furthermore, this study reveals that being an involuntarily childless Black African woman means having to deal with gruesome feelings of shame and stigma. Goffman (1963) defined stigma as:

“an attribute that is deeply discrediting so that the stigmatised will be reduced in the minds of others from a whole and usual person to a tainted and discounted one” (Goffman 1963, p.3).

Miall (1986) argued that the social stigma felt by childless couples is based on the fact that societies are pronatalist. Since involuntarily childless couples do not show any physical sign of their childlessness (Griel, 1991; Whiteford and Gonzalez, 1995), it may be seen as if the couples have chosen not to have children. However, this perception has been found not to hold in the context of the Black Africans, such as seen among the South Asian (Culley and Hudson, 2009) and the Middle Eastern (Inhorn and van Balen, 2002) communities, where it is more of a mandate than a mere desire to bear children. Some authors have even pointed out that the stigma infertile couples may feel, especially those in the highly pronatalist societies, may be caused by internalising some social norms which portray that all couples should *have* and should *want* to have children (Greil, 1991).

For Naomi, it could be suggested that her feelings of stigma may have been both internalised and external. She noted that at some point in time, she stopped attending social functions such as birthdays because no one invited her. There is a debate about the stigma that involuntarily childless couple perceive to feel. Forsythe (2009) suggests that such feelings stem from an external source, or is embedded in the minds of the couple. According to Greil (1991), infertility is a secret stigma hidden only in the couple's minds since there is no apparent evidence that a couple is infertile. The author opines that the reason a couple feels stigmatised is because they have internalised their society's norms regarding conception and childbirth (Greil, 1991), thereby making them feel out of place.

Another striking case of shame and stigma was that of Mary whose parents-in-law openly taunted her. Mary narrated how her mother-in-law introduced her to strangers or guest visitors as a childless daughter-in-law while her father-in-law name-called her for eating food in vain: she narrated, "*he would say [...] I was eating food for nothing because I couldn't have children....*" (P11 L331 – 343). The infertility study by Aseffa (2011) in Ethiopia supports this finding and highlights that a childless woman experiences all sorts of social discriminations from her husband, his relatives, neighbours and even her relatives and friends.

6.2.3 Coping with involuntary childlessness

Throughout all the interview transcripts, there was an overriding sense that though infertility has been very challenging and impacting in every aspect of their lives, the

women held a particularly strong *belief* as Christians that they are hopeful for their involuntarily childless situation to be resolved through their faith in God. Belief may be likened to a perpetual lens through which people view the world. In his exploration about the general belief that people have regarding *control*, Rotter (1996) presented two sides to a person's locus of control; the *internal locus* and the *external locus*. The author argues that individuals with an 'internal locus' of control are often adamant that an event or occurrence depends on a person's conduct or action; while those with an 'external locus' of control believe that occurrence depends on how lucky a person is, their fate, or powerful forces, and not necessarily on a person's own action (Rotter, 1996).

In this study, it was not difficult to decipher that almost all the women constantly made reference to God as the only powerful source (despite their knowledge of medical science) they believe will make them have children. Some authors in the past have argued that people are facing challenging situations; they are greatly influenced by their beliefs (Lazarus *et al.*, 1951). Without a doubt, the women in this study displayed what Rotter (1996) referred to as an *external* locus of control since they believed that their infertility could be resolved by God. As discussed in chapter two, a person who sees God as responsible for their childlessness may exhibit different forms and degrees of psychological reactions, which in turn could affect the person's trust in modern medicine (Greil, 1991; Inhorn 1996; Cooper-Hilbert, 1998).

Blessing, who is in her early 40s and has been trying to conceive after marriage for seven years, and has only just had basic investigations about her inability to conceive carried out in her country of origin, was firm about leaving everything to God. For Blessing, it was not relevance if her involuntary childlessness was medical or not but she expressed strong faith in God as the only solution to her childlessness. During her narrative, Blessing reflected back to a certain woman she knew who suffered involuntary childlessness for over 25 years, and concluded that despite the woman having accessed the most advanced and sophisticated ARTs, she claimed that she was finally pregnant naturally without any assistance from fertility treatment. This made Blessing lose faith in medical science. 'Control' as illustrated by Rotter (1996) is an important factor when trying to cope with involuntary childlessness. For instance unexplained infertility can have a broad meaning to people from different

cultural settings; in other words, the meaning attributed by different people to infertility will greatly be shaped by their beliefs (Kilbride, 2003; Rotter, 1996).

Coping is defined by Folkman and Lazarus (1980) as “a cognitive and behavioural efforts to master, reduce or tolerate the internal and/or external demands that are created by stressful transactions”. According to Folkman (1984), coping may serve two major purposes; (1) manage problematic situation (problem-focused); (2) regulate emotions (emotion-focused). Folkman suggests that an emotion-focused is activated when modifying the *meaning* of an occurrence or problematic situation, such as concentrating on the good part of a bad situation (Folkman, 1984).

In Theresa’s case, she focused her mind on the thoughts/ideas that her delay in conceiving and bearing children means that God has a plan to bless her with a set of twins which will make up for the lost years she used trying to conceive: “*Maybe God has his plan [...] I’ll just have twins and that’s it*” (Page 12 Line 309 – 317). While Theresa said she keeps touching her tummy to pray every night, Christy and Martha were quite firm about their faith in God as they narrated how they only cope better when they pray and read their Bible. This supports the findings by Toscano and Montgomery (2009) who explored the experiences of women post-IVF treatment. The authors highlight that most of their participants had a concrete relationship with God (Toscano and Montgomery 2009).

Blessing on the other hand was even more physical in her display of faith by acquiring baby items as a form of religious ritual/activity to invoke the blessing of a baby to her life. Some authors have noted that in recent times, faith and spirituality have gained scholarly recognition as important factors when trying to understand illness; used as a means of coping and support when faced with real life problems; and also used in clinical care settings (Kelleher and Hiller, 1996; Koeing *et al.*, 2001). According to Blyth and Landau (2009), “spirituality, formalised as religion, is an intrinsic part of all human cultures, feeding into a culture’s norms, laws and ideologies”. Regardless of their religion, people’s religiosity may affect their fertility pattern. Religiosity can be expressed in a number of ways which involves the active participation of faithful followers to be engaged in religious activities such as fellowshiping together with other believers, personal devotion to special religious

functions (e.g. fasting, prayers, pilgrimage) and family observance (Waite and Lehre, 2003).

For example, as all the participants in this study are Christians, most of them expressed that praying to God and attending church activities helped them not feel bad and overwhelmed with the pressure of infertility. Most Black Africans are known for being *quite* religious and committed to their religious activities (Tabong and Adongo, 2013; Hollos *et al.*, 2009; Donkor, 2008). As mentioned in chapter three, people of African and Caribbean origin make up 2 per cent of the UK population but interestingly account for more than two-thirds of churchgoers (John, 2005). Some authors have maintained that it is common place for developed countries to accept the biomedical interpretations and meaning of infertility; whereas in less developed countries, such interpretations are split between those that trust in medical science, and those who strongly believe that fertility problems are caused by powerful forces and may only be resolved traditionally (Dyer *et al.*, 2004; Nahar, 2007; Gerrits, 1997; Feldman-Savelsberg, 2002).

Religiosity has far-reaching positive effects on the mind and mentality of people. For instance, Waite and Lehrer (2003) cite a report into cancer risk that shows a difference of more than seven years at age 20 in life expectancy between those who actively involved in religious programs at least twice a week and those who do not attend. They cite studies suggesting a relationship between religious involvement and better mental health outcomes, educational attainment and subsequent economic wellbeing (Waite and Lehrer, 2003). Furthermore, studies of young people growing up in developed countries with some religious involvement show less likelihood of substance misuse, criminal behaviour, delay early engagement in sexual activities and an overall positive attitude towards settling into family life at the right time (Bearman and Bruckner, 2001; Donahue and Benson, 1995; Marchena and Waite, 2001).

Similar findings have been reported by Hudson and colleagues in their exploration of infertility perceptions and experiences among South Asian communities in the UK. The authors found that religion is an important factor in framing and coping with infertility. They note that praying, fasting, embarking on pilgrimages and other religious rituals were often cited as processes that could possibly encourage

reproductive success, and most of their participants added that some members of their community would often engage in those religious rituals when they are faced with challenging situations (Hudson, 2008; Culley and Hudson, 2009; Culley *et al.*, 2009).

Drawing from what have been discussed in chapter three, Mahanty *et al.* (1991) mention that involuntary childlessness and its experiences do vary amongst individuals in society. While Martha and Mary seem all calm and relaxed even in the face of their fertility struggles, the same cannot be said about the experiences of Precious, Theresa and the other women in the study. Though all are from Nigeria except for Mary, their personal dealings and daily interactions with their socio-cultural environment impacted with a varying degree of pressure on them; and their ability to cope, adapt or even adjust to the pressure was solely personal.

6.3 Methodological reflections

My position as a researcher and my identity as a Black African woman played an important role in this study. Dwyer and Buckle (2009) noted that an insider researcher is often able to engage participants with ease and the use of shared experience comes in handy in order to collect a richer data set. However, such position is equally laden with its challenge such as threat of confidentiality especially with members of the same community on sensitive issues (Serrant-Green, 2002).

As an insider, my position was versatile. As a Black African woman who had most of my socialisation in Africa, I have an understanding of the beliefs, culture, religion and the importance of motherhood in Africa. This insider status helped me understand the participants' narratives deeply and the understated messages in their stories. Moreover, being a really sensitive research area explored in a community where involuntary childlessness is highly stigmatised, my insider position paved way for an easy access for recruitment of the study participants as trust was not difficult to achieve after the establishment of initial rapport.

It was also to my advantage that coming from an ethnic minority and an under-researched group especially in this context, most of my participants expressed their appreciation that someone from their community who understands the significant of motherhood and the consequences of being childless will make their plight known

and voices heard in a research study in a Western society. Some women even explained at the end of the interview that they found the experience cathartic.

However, the challenge I encountered as an insider was the ability to keep reminding myself that I must not assume that I know ‘everything’ but that I must ask the ‘dump’ questions so that I get an answer from the participant. For instance, when I asked certain questions, I did get some reactions like “*c’mon you should know that already, are you not an African woman?*” Because participants expect that I already know the answer to certain question I ask.

Using IPA as a research method was the most suitable approach which allows the lived experiences of involuntary childless black women to be illuminated in its own terms because it allows the researcher to make sense of the participants making sense of their situation – a concept termed double hermeneutics in IPA (Smith *et al.*, 2009).

Like Smith and Osborn (2015) said, IPA is quite useful for exploring topics that are complex, ambiguous and emotionally laden and involuntary childlessness fit such prescription. IPA allows participants to give deep details of their lived experience which on one the hand requires a good level of skill from the researcher who should possess a strong empathetic ability to engage with his/her participant whilst being able to probe further into interesting and important aspect of their experience.

However, even as IPA brings all these valuable features to paint a whole and complete picture of the study, it does not lack its own challenges as a research method. IPA analytical steps can be time-consuming and laborious. Though Smith *et al.*, (2009) propose seven steps of analysing IPA whereby the authors said steps can be used flexibly depending on the researcher’s experience with IPA. Nevertheless, all steps are important in order to be able to pull-out all the themes from the data set. This is the more reason why IPA is strongly recommended on small sample size (Smith *et al.*, 2009; Smith and Osborn, 2015); so as to do justice to the explicitly idiographic nature of IPA.

6.4 Study strength and limitations and suggestions for future research

The findings from this study provide important information about Black African women's experiences of involuntary childlessness and infertility. There are however some limitations to this study which highlight the importance of further research in this area.

6.4.1 Strengths

- Sampling: the sampling was theoretically consistent with the requirements of qualitative research and IPA's orientation. A particular strength of this research is that Black African women were successfully recruited to participate in the study when people from BME backgrounds are regarded as 'hard to reach' for research purposes (Foster, 1998; Sheldon *et al.*, 2007; Elam and Fenton, 2003). The Black African community is also a relatively under researched BME group when compared for example to the South Asian community in the UK and are therefore less familiar with research. Recruiting participants purposively through community networks/contacts overcame some of these barriers and led to successful recruitment.
- Sensitivity: the evidence base highlights potential problems when recruiting participants for research in sensitive areas (Liamputtong, 2007; Dickson-Swift *et al.*, 2008; Watt and Liamputtong, 2013). Involuntary childlessness and infertility are sensitive topics for couples wanting children but in the pronatalist Black African community the stigma associated with not being able to have a child is heightened with women reluctant to disclose (or take part in research). This barrier was overcome by recruiting participants purposively through community networks/contacts.
- Insider/outsider status and depth of analysis: during the recruitment and data collection phase the researcher became very close to the participants and this helped with the depth of the analysis required for an IPA study and meant that the idiographic nature of phenomenology was achieved.
- Generalisability of findings: it is not intended for the findings of this study to be generalised to the population of the involuntarily childless or infertile Black African women across the UK; but this study seeks to understand how involuntary childlessness is experienced and perceived by women who are

facing the challenge, providing a context in which implications and ideas for further research can be done.

6.4.2 Limitations

- Sample: the sample for this study focused on involuntary childless women. As this study was only carried out among women, future studies could look at including involuntarily childless Black African men as well as exploring their experiences as a couple unit (Kilbride, 2003). It would also be useful to increase the diversity of the sample to include other ethnic groups to ascertain similarities and differences in experiences of involuntary childlessness (Salway *et al.*, 2009). In addition it would be useful to look at lay community perceptions of involuntary childlessness to ascertain a deeper understanding of the stigma associated with involuntary childlessness and infertility.
- Data on infertility by ethnicity: although data is available on prevalence of infertility in the UK (HFEA, 2006) and this was also available by ethnicity; what is lacking is data on infertile couples/women from BME communities utilisation of infertility services and ART in the UK (HFEA, 2006-2007; Culley *et al.*, 2004).

6.5 Contribution to the field

This study makes an important contribution to the field in three main ways:

Theoretically: To the best of the researcher's knowledge, this is one of the first studies to use phenomenology to explore Black African women's experiences of involuntary childlessness in the UK.

Methodologically: This is just one other study that is advancing the use of IPA in health research. Though quite popular in the field of psychology, IPA has been increasingly used in health researches (Bawadi, 2009; Loke *et al.*, 2012; Kilbride, 2003; Rapport, 2003; Hersherge and Kavanugh, 2008; Crete and Adamshick 2011). Using IPA in health research offers an explicit way to share the illness experiences of people to a wider audience (through publications) who are interested to know and understand the lived experiences of others.

Policy/service implications: What different people understand to be health and illness have continued to receive increasing recognition due to the *constructed* nature of illness. Healthcare providers such as health psychologists have realised the importance of understanding patients' perception and interpretation of their bodily experiences and what it means to them (Brocki and Wearden, 2006); which in this case is involuntary childlessness.

IPA allows for the exploration of such subjective experiences and helps the researcher to describe and understand the participants' account of the processes by which they make sense of their experiences. In other words, the meanings and interpretations the women in this study assign to their experience of involuntary childlessness is captured and portrayed in an epistemologically acceptable way for policy consideration. For instance, narratives from the study participants reveal that religious beliefs play an integral part in the lives of many Black African women as the transcripts highlight that almost all the women made reference to God as the solution to their childlessness. However, such belief did not prevent them from seeking medical attention. Thus, having this understanding may help fertility services to tailor their response to this increasingly diverse society to ensure that fertility services are delivered in a culturally and linguistically appropriate way.

6.6 Conclusion

The research question this study set out to address was: What is the experience of involuntary childlessness and infertility among Black African women in Luton? IPA provided a methodology and method to further this enquiry. The findings from this study highlight the uniqueness and complexities of involuntary childlessness and infertility as experienced by the study participants. The women who took part in this study shared common experience of 'the vulnerable self', 'self and the social world' and 'coping with involuntary childlessness or infertility'. The findings from this study provide important evidence highlighting the need to include Black African women's voices into the story of involuntary childlessness and infertility as a way of ensuring that infertility services meet the needs of this growing population.

References

- Abbey, A. Andrews, Frank. M. and Halrnan, J. (1991) 'Gender's role in responses to infertility', *Psychology of Women Quarterly*, 15(2), pp.295–316.
- Abarikwu, S. (2013) 'Causes and risk factors for male-factor infertility in Nigeria: a review', *African Journal of Reproductive Health*. 17(4): pp 150-166.
- Adler, P. and Adler, P. (1987) *Membership roles in field research*. Newbury Park, CA: Sage.
- Afek, D. (1990) 'Sarah and the women's movement: the experience of infertility'. *Women and Therapy*, 10, pp.195-203.
- Afiyanti, Y. and Milanti, A. (2013) 'Physical sexual and intimate relationship concerns among Indonesian cervical cancer survivors: a phenomenological study'. *Nursing and Health Sciences*, 15(2), pp.51–156.
- Aghanwa, H., Dare, F. and Ogunniyi, S. (1999) 'Sociodemographic factors in mental disorders associated with infertility in Nigeria', *Journal of Psychosomatic Research*. 46(2), pp.117–123.
- Ahmed, M., Chu, C. and Robson, F. (1998) 'Psycho-social implications of congenital bilateral absence of the vas deferens (male infertility) on Pakistani Muslim families. Paper presented at the 6th European meeting on psychosocial aspects of genetics', pp.1-3. Paris, France.
- Akinloye, O. and Truter, E. (2011) 'A review of management of infertility in Nigeria: Framing the ethics of a national health policy', *International Journal of Women's Health*, 3(1), pp.265–275.
- Akizuki, Y. and Kai, I. (2008) 'Infertile Japanese women's perception of positive and negative social interactions within their social networks', *Human Reproduction*, 23(12), pp.27-37.
- Araoye, M. (2003) 'Epidemiology of infertility: social problems of the infertile couples', *West African Journal of Medicine*, 22(2), pp.190–196 [online]. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/14529236> (Accessed: 28 March 2016).
- Arksey, H. and P. Knight (1999) *Interviewing social scientists*. London: Sage Publication.

- Aseffa, F. (2011) *Socio-cultural Perceptions of Infertility and their Implications : A Study of Women Experiencing Childlessness in South Gondar, Ethiopia*. (Unpublished MPhil thesis) Universitas Bergensis, Norway.
- Atwood, J. and Dobkin, S. (1992) 'Storm clouds are coming: ways to help couples reconstruct the crisis of infertility', *Contemporary Family Therapy*, 14(5), pp.385–403.
- Baluch, B., al-Shawaf, T. and Craft, I. (1992) 'Prime factors for seeking infertility treatment amongst Iranian patients', *Psychological Reports*, 71(1), pp.265–266.
- Baluch, B., Nasser, M. and Aghsa, M. (1998) 'Psychological and social aspects of male infertility in a male dominated society', *Journal of Social Evolutionary Systems*, 21, pp.113–120.
- Barden-O'Fallon, J. (2005) 'Unmet fertility expectations and the perception of fertility problems in a Malawian village', *African Journal of Reproductive Health*, 9(2), pp.14–25.
- Bawadi, H. (2009) *Migrant Arab Muslim women's experiences of childbirth in the UK* (Unpublished PhD thesis) De Monfort University, Leicester.
- Bearman, P. and Bruckner, H. (2001) "'Promising the future: virginity pledges and first intercourse.'" *American Journal of Sociology*, 106(4), pp.859-912.
- Beaurepaire, J., Jones, M., Thiering, P., Saunders, D. and Tennant, C. (1994) 'Psychosocial adjustment to infertility and its treatment: male and female responses at different stages of IVF/ET treatment', *Journal of Psychosomatic Research*, 38(3), pp.229–240.
- Becker, G. and Nachtigall, D. (1994) "'Born to be a mother": the cultural construction of risk in infertility treatment in the U.S.' *Social Sciences and Medicine*, 39, pp.507-518.
- Bell, K. (2013) 'Constructions of "infertility" and some lived experiences of involuntary childlessness', *Journal of Women & Social Work*, 28(3), pp.284–295.
- Belsey, M.A. (1976) 'The epidemiology of infertility: a review with particular reference to sub Saharan Africa', *Bulletin of the World Health Organization*, 54(3), pp.319–341.

- Berg, B. Wilson, F. and Weingartner, P. (1991) 'Psychological sequelae of infertility treatment: the role of gender and sex-role identification', *Social Sciences & Medicine*, 33, pp.1071-1080.
- Bhattacharya, S., Porter, M., Amalraj, E., Templeton, A., Hamilton, M., Lee, A. and Kurinczuk, J. (2009) 'The epidemiology of infertility in the North East of Scotland', *Human Reproduction*, 24(12), pp.3096–3107.
- Biggerstaff, D. and Thompson, A. (2008) 'Interpretative Phenomenological Analysis(IPA): a qualitative methodology of choice in Healthcare research', *Qualitative Research in Psychology*, 5, pp.173-183.
- Blyth, E. and Landau, R. (2009) *Third party assisted conception across cultures: social, legal and ethical perspectives*. London: Jessica Kingley.
- Boivin, J., Bunting, L., Collins, J. and Nygren, K. (2007) 'International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care', *Human Reproduction*, 22(6), pp.1506–1512.
- Bolsoy, N., Taspinar, A., Kavlak, O. and Sirin, A. (2010) 'Differences in quality of life between infertile women and men in Turkey', *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 39(2), pp.191–198.
- Bowling, A. (2009) *Research methods in health: investigating health and health services*. Berkshire, UK: Open University Press.
- Brannen, J. and Nilsen, A. (2011) 'Comparative biographies in case-based cross-national research: methodological considerations', *Sociology*, 45(4), pp.603-619.
- British Psychological Society (BPS) (2014) *Code of Human Ethics*. Leicester: The British Psychological Society [Online]. Available at: http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf (Accessed on: 14th July 2014).
- Brocki, J. and Wearden, A. (2006) 'A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology'. *Psychology & Health*, 21(1), pp.87–108.
- Brown, B. and Chor, J. (2014) 'Adding injury to injury: ethical implications of the Medicaid sterilization consent regulations', *Obstetrics and Gynecology*, 123(6): pp. 1348-1351.
- Bryman, A. (2001) *Social Research Methods*. 4th edn. Oxford: Oxford University Press.

- Bryman, A. (2012) *Social Research Methods*. 5th edn. Oxford: Oxford University Press.
- Bunting, L. and Boivin, J. (2008) 'Knowledge about infertility risk factors, fertility myths and illusory benefits of healthy habits in young people', *Human Reproduction*, 23(8), pp.1858–1864.
- Burns, L. and Covington, S. (1999) 'Psychology of infertility', in Burns, L. and Covington, S.H. (eds), *Infertility counselling: a comprehensive handbook for clinicians*. New York, London: Parthenon Publishing, pp.3–25.
- Bustfield, J. (1974) 'Ideologies and reproduction', in Richards, M. (ed), *The integration of the child into a social world*. Cambridge: Cambridge University Press.
- Carter-Edwards, L., Fisher, J., Vaughn, B. and Svetkey, L. (2002) 'Is this a viable mechanism for effectively recruiting African Americans for a community-based survey?', *Ethnicity and Health*, 7(2), pp.41-55.
- Carroll, K. (2012) 'Infertile? The emotional labour of sensitive and feminist research methodologies'. *Qualitative Research*, 13(5), pp.546-561
- Chachamovich, J., Chachamovich, E., Ezer, H., Fleck, M., Knauth, D. and Passos, E. (2010) 'Agreement on perceptions of quality of life in couples dealing with infertility'. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 39(5), pp.557–565.
- Chachamovich, J., Chachamovich, E., Fleck, M., Cordova, F., Knauth, D. and Passos, E. (2009) 'Congruence of quality of life among infertile men and women: findings from a couple-based study', *Human Reproduction*, 24(9), pp.2151–2157.
- Chamberlain, K. (2000) 'Methodolatry and qualitative health research', *Journal of Health Psychology*, 5, pp.285-296.
- Clark, A. (1998) 'The qualitative-quantitative debate: moving from positivism and confrontation to post-positivism and reconciliation', *Journal of Advanced Nursing*, 27(6), pp.1242-1249.
- Cooper-Hilbert, B. (1998) *Infertility and involuntary childlessness: helping couples cope*. New York: W. Norton & Company.
- Cousineau, T. and Domar, A. (2007) 'Psychological impact of infertility: best practice & research', *Clinical Obstetrics & Gynaecology*, 21(2), pp.293–308.

- Crete, J. and Adamshick, P. (2011) 'Managing polycystic ovary syndrome: what our patients are telling us', *Journal of Holistic Nursing*, 29(4), pp.256–266.
- Crossan, F. (2003). 'Research philosophy: towards an understanding', *Nurse Researcher*, 11(1), pp.46-55.
- Culley, L. and Hudson, N. (2009) 'Commonalities, differences and possibilities: culture and infertility in British South asian communities', in Culley, L., Hudson, N. and van Rooij, F. (eds.) *Marginalised reproduction: ethnicity, infertility and reproductive technologies*. London: Earthscan, pp.97-116.
- Culley, L., Hudson, N., Johnson, M. Rapport, F., Katbamna, S. (2007a) "'I know about one treatment where they keep the egg somewhere": British South Asian community understandings of infertility and its treatment', *Diversity in Health and Social Care*, 4(2), 113–121.
- Culley, L., Hudson, N. and Rapport, F. (2007b) 'Using focus groups with minority ethnic communities: Researching infertility in British South Asian communities', *Qualitative Health Research*, 17(1), 102–112.
- Culley, L., Hudson, N., Rapport, F., Katbamna, S. and Johnson, M. (2006) 'British South Asian communities and infertility services', *Human fertility*, 9(1), 37–45.
- Culley, L., Rapport, F., Hudson, N. (2004) *A Study of the Provision of Infertility Services to South Asian Communities A Study of the Provision of Infertility Services to South Asian Communities Final Report*. To Department of Health. De Montford University, Leicester, (May), [online]. Available at: <http://www.dmu.ac.uk/documents/research-documents/health-and-life-sciences/reproduction-research/endopart/southasiancommunitiesinfertilityexecutivesummary.pdf> (Accessed on: 23rd January 2016).
- Cwikel, J., Gidron, Y. and Sheiner, E. (2004) 'Psychological interactions with infertility among women', *European journal of obstetrics, gynecology, and reproductive biology*, 117(2), pp.126–131.
- Daniluk, J. (2001) "'If we had it to do over again...': couples' reflections on their experiences of infertility treatments', *The Family Journal*, 9(2), pp.122–133.
- De Kok, B. (2009) "'Automatically you become a polygamist'": 'culture' and 'norms' as resources for normalization and managing accountability in talk about responses to infertility', *An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13(2), pp.197-217.

- de Kok, B. and Widdicombe, S. (2008) ‘‘I really tried’’: Management of normative issues in accounts of responses to infertility’. *Social Science and Medicine*, 67 (7), pp.1083–1093.
- de Visser, R. and Smith, J. (2006) ‘Mister-in-between: A case study of masculine identity and health related behaviour’, *Journal of Health Psychology*, 11, pp.685-695.
- Dearden, G. (2009) *Transwomen’s memories of parental relationship: an interpretative phenomenological analysis study* (Unpublished PhD thesis.) University of Hertfordshire, Hertfordshire.
- Denny, E., Culley, L., Papadopoulos, I. and Apenteng, P. (2011) ‘From womanhood to endometriosis : findings from focus groups with women from different ethnic groups’, *Diversity in Healthcare*, pp.167–181.
- Department of Health (DoH). (2009) *Regulated fertility services: a commissioning aid* [Online]. Available at:
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101068.pdf (Accessed on: 16th November 2015).
- Department of Health DoH (2011) *No health without mental health: a cross-government mental health outcomes strategy for people of all ages* [online]. 2011. Policy. Available from:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf (Accessed: 23 March 2016).
- Dhont, N., van de Wijgert, J., Coene, G., Gasarabwe, A. and Temmerman, M. (2011) ‘‘Mama and papa nothing’’: Living with infertility among an urban population in Kigali, Rwanda’, *Human Reproduction*, 26(3), 623–629.
- Dickson-Swift, V., James, E., Kippen, S. and Liamputtong, R. (2008) ‘Risk to researchers in qualitative research on sensitive topics: issues and strategies’, *Qualitative Health Research*, 18(1), pp.133-144.
- Dimka, R. and Dein, S. (2013) ‘The work of a woman is to give birth to children: cultural constructions of infertility in Nigeria’, *African Journal Of Reproductive Health*, 17(2), 102–117.
- Domar, A. Seibel, M. (1997) ‘Emotional aspects of infertility’, in Seibel, M. (ed) *Infertility: a comprehensive text*. Norwalk, CT: Appleton and Lange; pp. 29–44.

- Donahue, M. and Benson, P. (1995) 'Religion and the well-being of adolescents', *Journal of Social Issues*, 51(2), pp145-160
- Donkor, E. (2008) 'Socio-cultural perceptions of infertility in Ghana', *Africa Journal of Nursing and Midwifery*, 10(1), pp22-34.
- Donkor, E. and Sandall, J. (2007) 'The impact of perceived stigma and mediating social factors on infertility-related stress among women seeking infertility treatment in Southern Ghana', *Social Science and Medicine*, 65(8), pp.1683-1694.
- Doughty, S. (2013) 'White Britons are now a minority in Leicester, Luton and Slough and Birmingham is set to follow by end of decade'. *Daily Mail*, 10 January 2013 [Online]. Available at: <http://www.dailymail.co.uk/news/article-2260067/White-Britons-minority-Leicester-Luton-Slough-Birmingham-set-follow-end-decade.html> (Accessed on: 2nd July 2014).
- Draper, A. and Swift, J (2011) 'Qualitative research in nutrition and dietetics: data collection issues', *Journal of Human Nutrition and Dietetics*, 24(1), pp.3-12.
- Dubard, A. and Gizlice, Z. (2008) 'Language spoken and differences in health status, access to care, and receipt of preventive services among US hispanics', *American Journal of Public Health*, 98(11), pp.2021-2028.
- Dwyer, S. and Buckle, J. (2009) 'The space between: on being an insider-outsider in qualitative research', *International Journal of Qualitative Methods*, 8(1), pp.54-63.
- Dyer, S., Abrahams, N., Hoffman, M. and van der Spuy, Z.M. (2002a) "'Men leave me as I cannot have children": women's experiences with involuntary childlessness', *Human Reproduction*, 17(6), pp.1663-1668.
- Dyer, S., Abrahams, N., Hoffman, M. and van der Spuy, Z.M. (2002b) 'Infertility in South Africa: women's reproductive health knowledge and treatment-seeking behaviour for involuntary childlessness', *Human reproduction*, 17 (6), pp.1657-1662.
- Dyer, S., Abrahams, N., Mokoena, N.E. and van der Spuy, Z.M. (2004) "'You are a man because you have children": experiences, reproductive health knowledge and treatment-seeking behaviour among men suffering from couple infertility in South Africa', *Human Reproduction*, 19(4), pp.960-967.

- Dyer, S., Abrahams, N. Mokoena, N. Lombard, C., van der Spuy, Z. (2005) 'Psychological distress among women suffering from couple infertility in South Africa: a quantitative assessment', *Human Reproduction*, 20(7), pp.1938–1943.
- Ebomoyi, E. and Adetoro, O. (1990) 'Socio-biological factors influencing infertility in a rural Nigerian community', *International Journal of Gynecology and Obstetrics*, 33(1), 41–47.
- Elam, G. and Fenton, K. (2003) 'Researching sensitive issues and ethnicity: lessons from sexual health'. *Ethnicity and Health*, 8(1), pp.15–27.
- Fadare, J. and Adeniyi, A. (2015) 'Ethical issues in newer assisted reproductive technologies: a view from Nigeria'. *Nigerian Journal of Clinical Practice*, pp.57-61.
- Farland, P. and Caron, S. (2013) 'The transition to biological childlessness: interviews with women who are infertile and remained childless', *The Family Journal*, 21, pp.180-188.
- Feldman-Savelsberg P. (2002) 'Is infertility an unrecognized public health and population problem?: the view from the Cameroon grass fields, in: Inhorn, M. and van Balen, F. (ed) *Infertility around the globe: new thinking on childlessness, gender, and reproductive technologies: a view from the social sciences*. Berkeley, CA: University of California Press.
- Finlay, L. (2008) *Introducing phenomenological research* [Online]. Available at: <http://www.lindafinlay.co.uk/phenomenology.htm> (Accessed: 23 June 2015).
- Fisher, L. (2009) *Infertility and assisted reproduction, in, Mental health aspects of women's reproductive health: a global review of the literature*. Geneva, Switzerland: World health Organisation, pp.128-146.
- Fledderjohann, J. (2012) "'Zero is not good for me": Implications of infertility in Ghana', *Human Reproduction*, 27(5), pp.1383–1390.
- Flick, U. (2000) *Qualitative inquiries into social representations in knowledge and language*. Cambridge: Cambridge University Press.
- Folkman, S. (1984). 'Personal control and stress and coping processes: A theoretical analysis'. *Journal of Personality and Social Psychology*, 46,839-852.
- Folkman, S. and Lazarus, R. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour*. 21,219-239.

- Folkvord, S. Odegaard, O. and Sundby, J. (2005) 'Male infertility in Zimbabwe.' *Patient education and counseling*. 59 (3), 239–243 [online]. DOI: 10.1016/j.pec.2005.08.003 (Accessed: 1 April 2016).
- Fontes, L. (2004) 'Ethics in violence against women research: the sensitive, the dangerous, and the Overlooked', *Ethics and Behaviour*, 14(2), pp.141–174.
- Forsythe, S. (2009) 'Social stigma and the medicalisation of infertility', *Journal of the Manitoba Anthropology Students' Association*, 28, pp.22–36.
- Foster, K. (1998) Evaluating nonresponse on household surveys, general social survey methodology series No.8, London: Government Statistical Service.
- Fouquier, K. (2011) 'The concept of motherhood among three generations of African American women', *Journal of Nursing Scholarship*, 43(2), pp.145–153.
- Fulford, B., Bunting, L., Tsibulsky, I. and Boivin, J. (2013) 'The role of knowledge and perceived susceptibility in intentions to optimize fertility: findings from the International Fertility Decision-Making Study (IFDMS)', *Human reproduction*, 28(12), pp.3253–3262.
- Furnham, A. and Malik, R. (1994) 'Cross-cultural beliefs about 'depression'', *International Journal of Social Psychiatry*, 40(2), pp.106–123.
- Geelhoed, D., Nayembil, D., Asare, K. Schagen van Leeuwen, J. and van Roosmalen, J. (2002) 'Infertility in rural Ghana', *International Journal of Gynecology and Obstetrics*, 79(2), pp.137–142.
- Gerrits, T. (1997) 'Social and cultural aspects of infertility in Mozambique', *Patient Education and Counselling*, 31(1), pp.39–48.
- Gillespie, R. (1999) 'Voluntary childlessness in the United Kingdom', *Reproductive Health Matters*, 7(13) pp.43–53.
- Ginsburg, F. and Rapp, R. (eds.) (1995) *Conceiving the new world order: the global politics of reproduction*. Berkeley: University of California Press.
- Glaser, B. and Strauss, A. (1965) *Awareness of dying*. Chicago, IL: Aldine Atherton.
- Goffman E (1963) *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- Golafshani, N. (2003) 'Understanding reliability and validity in qualitative research', *The Qualitative Report*, 8(4), pp.597–606.

- Gold, J. (2013) 'The experiences of childfree and childless couples in a pronatalistic society: implications for family counselors', *The Family Journal*, 21(2), pp.223–229.
- Gonzalez, L. (2000) 'Infertility as a transformational process: a framework for psychotherapeutic support of infertile women.' *Issues in Mental Health Nursing*, 21(6), pp.619–633.
- Greenhalgh, S. (1995) 'Anthropology theorizes reproduction: integrating practice, political economic, and feminist perspectives', in Greenhalgh, S. (ed.) *Situating fertility: anthropology and demographic inquiry*. Cambridge: Cambridge University Press, pp. 3-28.
- Greil, A, McQuillan, J. Lowry, M. and Shreffler, K. (2011) 'Infertility treatment and fertility-specific distress: a longitudinal analysis of a population-based sample of U.S. women', *Social Science and Medicine*, 73(1), pp.87–94.
- Greil, A. (1991) A secret stigma: an analogy between infertility and chronic illness and disability in Albrecht, G. and Levy, J. (eds.) *Advances in medical sociology*. Greenwich, CT: JAI Press, 2, pp.17-38.
- Greil, A. (1997) 'Infertility and psychological distress: A critical review of the literature', *Social Science and Medicine*, 45(11), pp.1679-1704.
- Greil, A., McQuillan, J. and Slauson-Blevins, K. (2011b) 'The social construction of infertility', *Sociology Compass*, 5(8), pp.736–746.
- Greil, A., Slauson-Blevins, K. and McQuillan, J. (2010) 'The experience of infertility: a review of recent literature', *Sociology of Health and Illness*, 32(1), pp.140–162.
- Greil, A., McQuillan, J., Shreffler, K., Johnson, K., and Slauson-Blevins, K. (2010) 'Race-ethnicity and medical services for fertility: stratified reproduction in a population-based of U.S. women', *Journal of Health and Social Behaviour*. 52(4): pp. 493-509.
- Griffiths, M. (2009) *Parent and child experience of childhood cancer: an interpretative phenomenological analysis approach* (Unpublished PhD thesis) Queensland University of Technology, Queensland.
- Grosios, K. Gahan, P. and Burbidge, J. (2010) 'Overview of healthcare in the UK'. *EPMA Journal*, 1(4) pp.529–534.
- Haile, A. (1990) 'Fertility conditions in Gondar, northwestern Ethiopia: an appraisal of current status', *Studies in Family Planning*, 21(2), pp.110–118.

- Hampshire, K., Blell, M. and Simpson, B. (2012) “‘Everybody is moving on’”: infertility, relationality and the aesthetics of family among British-Pakistani Muslims’, *Social Science and Medicine*, 74(7), pp.1045–1052.
- Harris, C. (2012) *The experiences of adoptive mothers: an interpretative phenomenological analysis* (Unpublished PhD thesis). University of East London.
- Harris, L. and Wolfe, T. (2014) ‘Stratified reproduction, family planning care and the double edge of history’, *Current Opinion Obstetrics and Gynecology*. 26(6): pp. 539-544.
- Harris, D. and Daniluk, J. (2010) ‘The experience of spontaneous pregnancy loss for infertile women who have conceived through assisted reproduction technology’, *Human Reproduction*, 25(3), pp.714–720.
- Hassa, H., Ayranci, U., Unluoglu, I., Metintas, S and Unsal, A. (2005) ‘Attitudes to and management of fertility among primary health care physicians in Turkey: an epidemiological study’, *BMC Public Health*, 5, pp.5-33.
- Heidegger, M. (1962). *Being and time*. Oxford, Basil Blackwell (original work published 1927).
- Helman, C. (2007) *Culture, Health and illness* (5th edn) London: Hodder Arnold.
- Hershberger, P. and Kavanaugh, K. (2008) ‘Enhancing pregnant, donor oocyte recipient women’s health in the infertility clinic and beyond: a phenomenological investigation of caring behaviour’, *Journal of Clinical Nursing*, 17(21), pp.2820–2828.
- HFEA (2006) *Communities urged to speak out to ensure they get the fertility services they need - HFEA press release* [Online]. Available at: <http://www.hfea.gov.uk/577.html> (Accessed: 8 March 2015).
- HFEA (2011) *Fertility treatment in 2011 - trends and figures*. 7 [Online]. Available at: http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2011_-_Annual_Register_Report.pdf.
- HFEA (2012) *Fertility treatment in 2012 trends and figures* [Online]. Available at: <http://www.hfea.gov.uk/docs/FertilityTreatment2012TrendsFigures.PDF> (Accessed on: 16th April 2015).

- HFEA (2013a) *Fertility treatment in 2013 trends and figures* [Online]. Available from:
http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2013.pdf
 (Accessed on: 16th April 2015).
- HFEA (2013b) *HFEA's response to the updated NICE guidance on fertility* [Online]. Available at: <http://www.hfea.gov.uk/7756.html> (Accessed on: 16th April 2015).
- HFEA (2014a) *Your fertility treatment options* [Online]. Available at:
<http://www.hfea.gov.uk/fertility-treatment-options.html> (Accessed on 10/12/2016).
- HFEA (2014b) *Fertility treatment 2014: trends and figures* [Online]. Available at:
http://www.hfea.gov.uk/docs/HFEA_Fertility_treatment_Trends_and_figures_2014.pdf (Accessed on 10/12/2016).
- Hoffman, L. and Hoffman, M. (1973) 'The value of children to parents', in Fawcett, J. (ed.) *Psychological perspectives on population*. New York: Basic Books Incoporation, pp.19-76.
- Hoffman, T. (2015) *Infertility and social media: how to handle online shaming*. Available at: <https://www.seleni.org/advice-support/article/coping-with-infertility-in-the-digital-age> (Accessed on: 16th January 2016).
- Hollos, M. (2003) 'Profiles of infertility in southern Nigeria: women's voices from Amakiri', *African journal of reproductive health*, 7 (2), pp.46–56.
- Hollos, M., Larsen, U., Obono, Oka. and Whitehouse, B. (2009) 'The problem of infertility in high fertility populations: meanings, consequences and coping mechanisms in two Nigerian communities', *Social Science and Medicine*, 68 (11), pp.2061–2068.
- Hotopf, M., Mayou, R., Wadsworth, M. and Wessely, S. (1998) 'Temporal relationships between physical symptoms and psychiatric disorder: results from a national birth cohort', *British Journal of Psychiatry*, 173, pp.255–261.
- Hudson, N. (2008) *Infertility in British South Asian communities: negotiating the community and the clinic* (unpublished PhD thesis), De Monfort University, Leicester.
- Hudson, N. (2012) 'Researching infertility in British South Asian communities: reflecting on intersection of ethnicity, age, gender and reproductive identity', *Diversity and Equality in Healthcare*, 9(3), pp.191-200.

- Husserl, E. (1964) *The Idea of Phenomenology*. Dordrecht: Kluwer Academic.
- Ibisomi, L. and Mudege, N. (2013) 'Childlessness in Nigeria: perceptions and acceptability', *Culture, Health and Sexuality*, *An International Journal for Research, Intervention and Care*, 16(1), pp.61-75.
- Ibisomi, L. and Mudege, N. (2013) 'Childlessness in Nigeria: perceptions and acceptability'. *Culture, Health and Sexuality*, 16(1), pp.61-75.
- Inhorn, M. (1994) 'Interpreting infertility: Medical anthropological perspectives. Introduction', *Social Science and Medicine*, 39(4), pp.459-461.
- Inhorn, M. (1996) *Infertility and Patriarchy: the cultural politics of gender and family life in Egypt*. Philadelphia: University of Pennsylvania.
- Inhorn, M. (2003) 'Global infertility and the globalization of new reproductive technologies: Illustrations from Egypt', in *Social Science and Medicine*.
- Inhorn, M. and Buss, K. (1994) 'Ethnography, epidemiology and infertility in Egypt', *Social Science Medicine*, 39(5), pp.671-86.
- Inhorn, M. and van Balen, F. (2002) *Infertility around the globe: new thinking on childlessness, gender and reproductive technologies*. University of California Press: California.
- Jenkins, G. (2002) 'Childlessness, adoption, and Milagros de Dios in Costa Rica', in Inhorn, M. and van Balen, F. (eds.) *Infertility around the globe: new thinking on childlessness, gender, and reproductive technologies*. Berkeley, CA: University of California Press, pp.171-198.
- Johansson M, and Berg, M. (2005) 'Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment', *Scandinavian Journal of Caring Sciences*, 19(1), pp.58-63.
- Johansson, M. and Berg, M. (2005) 'Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment', *Scandinavian Journal of Caring Sciences*. 19(1), pp.58-63.
- Johansson, M., Adolfsson, A., Berg, M. Francis, J., Hogström, L. Janson, P. , Sogn, J. and Hellström, A. (2010) 'Gender perspective on quality of life, comparisons between groups 4-5.5 years after unsuccessful or successful IVF treatment', *Acta obstetrica et gynecologica Scandinavica*. 89(5), pp.683-691.

- John, C. (2005) 'Black worshippers keep the faith', *BBC New*, 1 August 2005.
[Online]. Available at: <http://news.bbc.co.uk/1/hi/uk/4704925.stm> (Accessed on: 4th Feb 2015).
- Johnson, M. (2006) 'Engaging communities and users: health and social care research with ethnic minority communities', in Nazroo, J. (ed.) *Health and social research in multi-ethnic societies*. London: Routledge, pp. 48-64
- Katbamna, S. (2000) 'Race' and childbirth [Online]. Available from: <http://stage-new.mcgraw-hill.co.uk/openup/chapters/0335199461.pdf> (Accessed: 23 March 2014).
- Katon, W. Walker, E. (1998) 'Medically unexplained symptoms in primary care'. *Journal of Clinical Psychiatry*, 59 (20), pp.15-21.
- Kauffman, K. (1994) 'The insider/outsider dilemma: field experience of a white researcher 'getting in' a poor black community', *Nursing Research*, 43(3), 179–183.
- Kelleher, D. and Hiller, S. (eds.) (1996) *Researching cultural differences in health*. London: Routledge.
- Kerr, J., Brown, C. and Balen, A. (1999) 'The experiences of couples who have had infertility treatment in the United Kingdom: results of a survey performed in 1997', *Human reproduction*, 14(4), pp.934–938.
- Kielmann, K. (1998) Barren ground: contesting identities of infertile women in Pemba, Tanzania, in Lock, M. and Kuufert, P. (eds.) *Pragmatic women and body politics* Cambridge: Cambridge University Press, pp.127–163.
- Kilbride, A. (2003) *How couples appraise and communicate about their fertility A study using Interpretative Phenomenological Analysis* (Unpublished PhD thesis), The University of Hull. Yorkshire.
- Koch, T. (2006) 'Establishing rigour in qualitative research: the decision trail' *Journal of Advanced Nursing*, 53(1) pp.91-103.
- Koenig, H, McCullough, M. and Larson, D. (2001) *Handbook of religion and health*. Oxford: Oxford University Press.
- Lampman, C. and Dowling-guyer, S. (1995) 'Attitudes toward voluntary and involuntary childlessness', *Basic and Applied Social Psychology*. 17 (1-2), pp.213–222.

- Lane, S. (1994) 'From population control to reproductive health: an emerging policy agenda', *Social science and medicine*, 39(9), pp.1303–1314.
- Larkin, M., Watts, S. and Clifton, E. (2006) 'Giving voice and making sense in interpretative phenomenological analysis', *Qualitative Research in Psychology*, 3(2), pp.102–120.
- Lavender, T., Platt, M., Tsekiri, E., Casson, I., Byrom, S., Baker, L. Walkinshaw, S. (2010) 'Women's perceptions of being pregnant and having pregestational diabetes', *Midwifery*, 26(6), pp.589–595.
- Laverty, S. (2003) 'Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations', *International Journal of Qualitative Methods*, 2(3).
- Lavie, M., and Willig, C. (2005) "'I don't feel like melting butter': an interpretative phenomenological analysis of the experience of 'inorgasmia'", *Psychology and Health*, 20(1), pp.115–128.
- Lazarus, R. Eriksen, C. and Fonda, C. (1981) 'Personality dynamics and auditory perceptual recognition', *Journal of Personality*, 19, pp.471–482.
- Lee, R. (1993) *Doing research on sensitive topics*. London: Sage.
- Lee, A. (1991) 'Integrating positivist and interpretive approaches to organisational research', *Organisation Science*, 2(4), pp.342–365.
- Leke, R., Oduma, J., Bassol-Mayagoitia, S., Bacha, A. and Grigor, K. (1993) 'Regional and geographical variations in infertility: effects of environmental, cultural, and socioeconomic factors', *Environmental Health Perspectives*, 101, pp.73–80.
- Lemon, N. and Taylor, H. (1997) 'Caring in casualty: the phenomenology of nursing care' in Hayes, N. (ed.) *Doing qualitative analysis in psychology*. Hove: Psychology Press, pp.227–243.
- Lester, S. (1999) An introduction to phenomenological research, Taunton: *Stan Lester Developments*. [Online]. Available at: <https://www.rgs.org/NR/rdonlyres/F50603E0-41AF-4B15-9C84-BA7E4DE8CB4F/0/Seaweedphenomenologyresearch.pdf> (Accessed: 1 April 2014).
- Letherby, G. (1999) Other than mother and mothers as others: the experience of motherhood and non-motherhood in relation to 'infertility' and 'Involuntary childlessness', *Women's Studies International Forum*, 22(3) pp.359–372.

- Letherby, G. (2002) 'Challenging dominant discourses: identity and change and the experience of "infertility" and "involuntary childlessness"', *Journal of Gender Studies*, 11(3), pp.277–288.
- Leung, C., Fan, A. and Sanders, M. (2013) 'The effectiveness of a group triple p with Chinese parents who have a child with developmental disability: a randomized controlled trial', *Research in Developmental Disabilities*, 34, pp.976-984.
- Levin, D. (1988) *The opening of vision: Nihilism and the postmodern situation*. London: Routledge.
- Lewis-Beck, M., Bryman, A. and Liao, T. (2004) *The Sage encyclopaedia of social science research methods*. London: Sage
- Liamputtong, P. (2007) *Recruiting the vulnerable: a guide to sensitive research methods*. London: Thousand Oaks.
- Loftus, J. and Namaste, P. (2011) *Expectant Mothers: Women's Infertility and the potential identity of biological motherhood*, 1, pp.1–20.
- Loke, A., Yu, P. and Hayter, M. (2012) 'Experiences of sub-fertility among Chinese couples in Hong Kong: a qualitative study', *Journal of Clinical Nursing*, 21 (3-4), pp.504–512.
- Macaluso, M., Wright-Schnapp, T., Chandra, A., Johnson, R., Satterwhite, C., Pulver, A. Berman, S., Wang, R., Farr, S. and Pollack, L. (2010) 'A public health focus on infertility prevention, detection, and management', *Fertility and Sterility*, 93(1).
- Madill, A., Jordan, A. and Shirley, C. (2000) 'Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies', *British Journal of Psychology*, 91, pp.1-20.
- Makoba, L. (2005) *The experiences of infertile married African women in South Africa: a feminist narrative inquiry* (Unpublished Masters of Art thesis) University of Pretoria, South Africa.
- Malik, S. and Coulson, N. (2013) 'Coming to terms with permanent involuntary childlessness: a phenomenological analysis of bulletin board postings', *Europe's Journal of Psychology*, 9(1), pp.77–92.

- Marchena, E. and Waite, L. (2001) 'Marriage and childbearing attitudes in late adolescence: gender, race and ethnic differences'. Revised version of paper presentation at the meeting of the Population Association of America, March 2000. Los Angeles, CA. USA.
- Mayhew, L. and Waples, S. (2011) *The growth and changing complexion of Luton's population: a structural analysis and decomposition*, [Online]. Available at: <http://www.luton.gov.uk/environment/lists/lutondocuments/pdf/planning/observatory/growth%20of%20luton%20population.pdf> (Accessed on: 23rd September 2014).
- McCarthy, P. (2008) 'Women's lived experience of infertility after unsuccessful medical intervention', *Journal of Midwifery and Women's Health*, 53(4), pp.319–324.
- McGoldrick, M., Preto, N., Hines, P. and Lee, E. (1991) 'Ethnicity in family therapy', in Gurman, A. and Knistern, D. (eds.), *Handbook of family therapy*, New York: Brunner/Mazel pp.558-579.
- McGrade, J. and Talor, A. (1981) 'The reaction to infertility investigation: a comparison of the responses of men and women', *Infertility*, 4, pp.7-27.
- McQuillan, J., Greil, A., White, L. and Jacob, M. (2003) 'Frustrated fertility: infertility and psychological distress among women', *Journal of Marriage and Family*, 65(4), pp.1007-1018.
- Menning, B. (1982) 'The psychosocial impact of infertility', *The Nursing Clinics of North America*, 17, pp.155–163.
- Merriam, S. (2009) *Qualitative research: A Guide and Implementation*. San Francisco, CA: Jossey-Bass.
- Miall, C. (1986) 'The stigma of involuntary childlessness', *Social Problems*, 33, pp.268-82.
- Miall, C. (1994) 'Community constructs of involuntary childlessness: sympathy, stigma, and social support', *Canadian Review of Sociology*, 31(4), pp.392–421.
- Mogobe, D. (2005) 'Denying and preserving self: Batswana women's experiences of infertility', *African Journal of Reproductive Health*, 9, pp.26–37.
- Mohanty, C., Russo, A. and Torres, L. (1991) *Third world women and the politics of feminism*. Bloomington: Indiana University Press.

- Molock, S. (1999) 'Racial, cultural and religious issues in infertility counselling', in Burns, L. and Covington, A. (eds.) *Infertility Counselling: a Comprehensive Handbook for Clinicians*. New York: Parthenon Publishing.
- Moran, D. (2000). *Introduction to phenomenology*. London: Routledge.
- Moran, D. (2005). *Edmund Husserl: Founder of Phenomenology*. Cambridge, Polity.
- Morell, C. (1994) *Unwomanly conduct: the challenges of intentional childlessness*. London: Routledge.
- Moules, N. (2002) "'Hermeneutic inquiry: paying heed to history and hermes 'an ancestral, substantive, and methodological tale'" *International Journal of Qualitative Methods*, 1(3) pp.1-40.
- Naab, F., Brown, R. and Heidrich, S. (2013) 'Psychosocial health of infertile Ghanaian women and their infertility beliefs', *Journal of Nursing Scholarship*, 45(2), pp.132–140.
- Nahar, P. (2007) *Childless in Bangladesh: suffering and resilience among rural and urban women* (Unpublished PhD thesis) University of Amsterdam, Amsterdam.
- Nahar, P. (2010) 'Health seeking behaviour of childless women in Bangladesh: an ethnographic exploration for the special issue on loss in child bearing', *Social Science and Medicine*, 71(10), pp.1780–1787.
- National Institute for Clinical Excellence – NICE (2004) *Fertility: assessment and treatment for people with fertility problems*. National Institute for Clinical Excellence, London.
- Nazroo, J. (1997) *The health of Britain's ethnic minorities: findings from a national survey*. London: Policy Studies Institute.
- Nazroo, J. (2003) 'The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism', *American Journal Of Public Health*, 93(2), pp.277–284.
- Nazroo, J., Falaschetti, E., Pierce, M. and Primatesta, P. (2009) 'Ethnic inequalities in access to and outcomes of healthcare: analysis of the health survey for England', *Journal of Epidemiology And Community Health*, 63(12), pp.1022–1027.

- Nazroo, J., Jackson, J., Karlsen, S. and Torres, M. (2007) 'The Black diaspora and health inequalities in the US and England: does where you go and how you get there make a difference?', *Sociology of Health and Illness*, 29(6), pp.811–830.
- Newill, R. (1974) *Infertile Marriage*. Middlesex: Penguin Books.
- NICE (2013b) *Fertility problems: assessment and treatment* [Online]. Available at: <https://www.nice.org.uk/guidance/cg156> (Accessed on: 17th June 2015).
- NICE (2014) *NICE calls for an end to postcode lottery of IVF treatment* / *News and features* / *News* / *NICE* [Online]. Available at: <https://www.nice.org.uk/news/article/nice-calls-for-an-end-to-postcode-lottery-of-ivf-treatment> (Accessed: 28 March 2016).
- NICE (2015) *NICE pathways: fertility overview* [Online]. Available at: <http://pathways.nice.org.uk/pathways/fertility> (Accessed on: 17th June 2015).
- Oakley, A. (1981) 'Interviewing women: a contradiction in terms', in Roberts, H (ed.) *Doing Feminist Research*. London: Routledge and Kegan Paul.
- Oakley, L. (2011) *The epidemiology of infertility: measurement, prevalence and an investigation of early life and reproductive risk factors* (Unpublished PhD thesis), London School of Hygiene Tropical Medicine, London.
- Oakley, L., Doyle, P. and Maconochie, N. (2008) 'Lifetime prevalence of infertility and infertility treatment in the UK: results from a population-based survey of reproduction', *Human Reproduction*, 23(2), pp.447–450.
- Obono, O. (2004) 'Life histories of infertile women in Ugep, Southern Nigeria', *African Population Studies*, 19, pp.63–88.
- Office for National Statistics – ONS (February 2010) *Current estimates – population estimates by ethnic groups Mid-2007 (experimental)*.
- Office of National Statistics – ONS (2011) *Neighbourhood Statistics: Ethnic Groups, 2011* [Online]. Available at: <http://www.neighbourhood.statistics.gov.uk/dissemination/LeadTableView.do?a=7&b=6275157&c=luton&d=13&e=13&g=6394327&i=1001x1003x1004&m=0&r=1&s=1459901487061&enc=1&dsFamilyId=2477&nsjs=true&nsck=false&nssvg=false&nswid=1366> (Accessed on: 23rd November 2014).
- Office for National Statistics – ONS (May 2010) *Population by country of birth and nationality, Oct 2008 to Sep 2009. (Double check in text)*

- Okonofua, F., Harris, D., Odebiyi, A. and Kane, T. (1997) 'The social meaning of infertility in Southwest Nigeria', *Health Transition Review*, 7(930), pp.205–220.
- Oliver, M. and Shapiro, T. (1995) *Black wealth/White wealth: a new perspective on racial inequality*. New York, NY: Routledge.
- Ombelet, W. and Campo, R. (2007) 'Affordable IVF for developing countries.' *Reproductive biomedicine online*, 15(3), pp.257–265.
- Omoaregba, J., James, B., Lawani, A. Morakinyo, O. and Olotu, O. (2011) 'Psychosocial characteristics of female infertility in a tertiary health institution in Nigeria', *Annals of African Medicine*, 10(1), pp.19–24.
- Osazuwa, F., Aigubaruueghian, O., Alekwe, L., Imade, P., Ibadin, K. and Aberare, L. (2013) 'The prevalence of Chlamydia trachomatis infection among infertile males and its association with abnormal semen characteristics in Delta State, Nigeria'. *Tanzania Journal of Health Research*, 15(2): pp.1-6.
- Owen, D. (1986) *The desire for children: a sociological study of involuntary childlessness* (Unpublished PhD thesis) University college Cardiff, Cardiff.
- Papreen, N., Sharma, A., Sabin, K., Begum, L., Ahsan, K. and Baqui, A. (2000) 'Living with infertility: experiences among urban slum populations in Bangladesh', *Reproductive Health Matters*, 8(15), pp.33–44.
- Parry, D. and Shinew, K. (2004) 'The constraining impact of infertility on women's leisure lifestyles', *Leisure Sciences*, 26(3), pp.295-308.
- Pasch, L. (1994) Fertility problems and marital relationships: the effect of appraisal and coping differences on communication, (Unpublished PhD thesis) University of California, Los Angeles.
- Pashigian M. (2002) Conceiving the happy family: infertility and marital politics in Northern Vietnam, in: Inhorn M. and van Balen, F. (eds.) *Infertility around the globe: new thinking on childlessness, gender, and reproductive technologies, a view from the social sciences*. Berkeley, CA: University of California Press.
- Patel, V. and Oomman, N. (1999) 'Mental health matters too: gynaecological morbidity and depression in South Asia', *Reproductive Health Matters*, 7(14), pp.30-38.
- Patton, M. (1990) *Qualitative Evaluation and Research Methods* (2nd edn). Newbury Park, CA: Sage.

- Payne, D., Goedeke, S., Balfour, S. and Gudex, G. (2011) 'Perspectives of mild cycle IVF: a qualitative study', *Psychology and Counselling*, 27(1), pp.167 – 172.
- Pearce T (1999) 'She will not be listened to in public: perceptions among the Yoruba of infertility and childlessness in women', *Reproductive Health Matters*, 7, pp.69-79.
- Peddie, V., van Teijlingen, E. and Bhattacharya, S. (2005) 'A qualitative study of women's decision-making at the end of IVF treatment', *Human Reproduction*, 20(7), pp.1944–1951.
- Peters, K., Jackson, D. and Rudge, T. (2011) 'Surviving the adversity of childlessness: fostering resilience in couples', *Contemporary Nurse*, 40(1), pp.130–140.
- Pilcher, H. (2006) 'IVF in Africa: fertility on a shoestring' [Online]. *Nature*, 442; pp975-977. Available at:
<http://www.nature.com/nature/journal/v442/n7106/full/442975a.html>
 (Accessed: 15/12/2016).
- Pfeffer, N. and Woollett, A. (1983) *Women's Experience of Infertility*. London: Virago.
- Pottinger, A., Mckenzie, C., Fredericks, J., Dacosta, V., Wynter, S., Everett, D. and Walters, Y. (2006) 'Gender differences in coping with infertility among couples undergoing counselling for in vitro fertilization treatment', 55(876), pp.237–242.
- Powell, B. (2001). 'Myths of fertility: demeter and the great goddess', in Powell, B. (ed.) *Classical myth* (3rd edn.) New Jersey: Prentice hall, pp.216-247.
- Rapport, F. (2003) 'Exploring the beliefs and experiences of potential egg share donors', *Journal of Advanced Nursing*, 43(1), pp.28–42.
- Rashid, S. (2007) 'Kal dristi , stolen babies and 'blocked uteruses': poverty and infertility anxieties among married adolescent women living in a slum in Dhaka, Bangladesh'. *Anthropology and Medicine*, 14(2), pp.153–166.
- RCN (2009) *RCN policy briefing 16/2009: Infertility provision in England* [Online]. Available at:
https://www2.rcn.org.uk/_data/assets/pdf_file/0003/311808/Infertility_provision_in_England.pdf (Accessed: 23 March 2016).

- Rees, C. (2003) *An introduction to Research for Midwives*. London, Book for Midwives.
- Remennick, L. (2000) 'Childless in the land of imperative motherhood: stigma and coping among infertile Israeli women', *Sex Roles*, 43(11-12), pp.821–841.
- Riessman, C. (2000) 'Stigma and everyday resistance practices: childless women in South India', *Gender and Society*, 14(1) pp111–135.
- Roberts, D. (1993) 'Racism and patriarchy in the meaning of motherhood', *Gender and Law*, pp.11–38.
- Roberts, D. (1997) *Killing the black body: race, reproduction, and the meaning of liberty*. Vintage: New York.
- Roessler, J. (2009) 'Perceptual experience and perceptual knowledge', *Mind*, 118 (472), pp.1013–1041.
- Rolfe, G. (2006) 'After critique', *Journal of Psychiatric and Mental Health Nursing*, 13(3), pp.373-377.
- Rosenstock, I. (1990) 'The health belief model: explaining health behavior through expectancies', *Health Behavior and Health Education*, pp.39–61.
- Rotter, J. (1966) 'Generalised expectancies for internal versus external control of reinforcement: psychological monographs', *General and Applied*, 80(1), pp 609.
- Salway, S., Allmark, P., Barley, R., Higginbottom, G., Gerrish, K. and Ellison, G. (2009) 'Researching ethnic inequalities', *Social Research Update*, 58.
- Sami, N. and Saeed, T. (2012) 'Perceptions and experiences of women in Karachi, Pakistan regarding secondary infertility: results from a community-based qualitative study', *Obstetrics and Gynecology International*, 20(12), pp.1–7.
- Schacter, D. Gilbert, D. and Wegner, D. (2011) *Psychology* (2nd edn) New York: Worth.
- Schyve, P. (2007) 'Language differences as a barrier to quality and safety in health care: The joint commission perspective', *Journal of General Internal Medicine*, 22 (2), pp.360–361.
- Seale, C. (1999) 'Quality in Qualitative Research', *Qualitative Inquiry*, 5(4), pp.465-478.

- Senior, P. and Bhopal, R. (1994) 'Ethnicity as a variable in epidemiological research.', *BMJ*, 309 (6950), pp.327–330.
- Senderwitz, E. (1974) *Pronatalism: the myth of mom and apple pie*. New York: Thompson Crowell.
- Serrant-Green, L. (2002) 'Black on black: methodological issues for black researchers working in minority ethnic communities', *Nurse Researcher*, 9 (4), pp.30–44.
- Sewpaul, V. (1999) 'Culture, religion and infertility: a South African perspective', *British Journal of Social Work*, 29(5), pp.741-754.
- Shapira, I. (2010) 'For infertile couples, Facebook is a minefield', *The Washington Post*, 25 October [Online]. Available at: <http://www.washingtonpost.com/wp-dyn/content/article/2010/10/24/AR2010102402856.html> (Accessed on: 6th May 2015).
- Sheldon, H., Graham, C., Pothcary, N. and Rasul, F. (2007) Increasing response rates amongst Black and minority ethnic and seldom heard groups: a review of the literature relevant to the national acute patient' survey. London: Picker Institute.
- Silverman, D. (2000) *Doing qualitative research: A practical handbook*. London: Sage.
- Simpson, B., Hampshire, K. and Blell, M. (2011) *British Pakistani Muslims , infertility and the new reproductive technologies : Summary of Findings*. Report. [Online]. Available at: <http://www.researchcatalogue.esrc.ac.uk/grants/RES-000-23-1488/read> (Accessed on: 4th March 2015).
- Smith, J. and Osborn, M. (2015) 'Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain', *British journal of Pain*. 9(1): pp 41-42.
- Smith, J. and Eatough, V. (2012) 'Interpretative phenomenological analysis', in Breakwell, G., Smith, J and Wright, D. (eds.) *Research methods in psychology* (4th edn) London: Sage, pp. 439-459.
- Smith, J. (1999) 'Identity development during the transition to motherhood: An interpretative phenomenological analysis', *Journal of Reproductive and Infant Psychology*, 17, pp.281-300.

- Smith, J. and Dunworth, F. (2003) 'Qualitative methodology' in Valsiner, J. and Connolly, K. (eds.) *Handbook of developmental psychology*. London: Sage, pp.603-621.
- Smith, J. and Eatough, V. (2007) 'Interpretative phenomenological analysis'. *Analysing qualitative data in psychology*, 35–51 [online]. DOI: 10.1002/9780470776278.ch10.
- Smith, J., Flowers, P. and Larkin, L. (2009) Interpretative Phenomenological Analysis: Theory, Method and Research', in Willig, C. and Stainton, R. (eds.) *Handbook of Qualitative Psychology*. London: Sage.
- Social Research Association (SRA) (2002) Ethical Guidelines. [Online]. Available at: <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf> (Accessed on 2nd March 2015).
- Sokolowski, R. (2000) *Introduction to Phenomenology*. Cambridge: Cambridge University Press.
- Stanley, L. and Wise, S. (1990) 'Method, methodology and epistemology in feminist research processes', in Stanley, L. (ed.) *Breaking out again: feminist ontology and epistemology*. London: Routledge.
- Stanton, A. and Dunkel-Schetter, C. (ed.) (1991) *Infertility: perspectives from stress and coping research*. New York: Plenum.
- Stiles, W. (1993) 'Quality control in qualitative research', *Clinical Psychology Review*, 13, pp.593-618.
- Strawson, P. (2008), 'Causation in perception', in *Freedom and resentment and other essays*, London: Routledge.
- Sullivan-Bolyai, S., Bova, C., Deatrick, J., Knafl, K., Grey, M., Leung, K. (2007) 'Barriers and strategies for recruiting study participants in clinical settings', *Western Journal of Nursing Research*, 29, pp.486-500.
- Sundby, J. and Jacobus, A. (2001) 'Women and infertility in sub-Saharan Africa', in Boerma, T. and Mgalla, Z. (eds.) *Health and traditional care in infertility: Experiences from the Gambia and Zimbabwe*, Amsterdam, The Netherlands: KIT, pp. 257–268.
- Sundby, J. (1997) 'Infertility in the Gambia: traditional and modern health care', *Patient Education and Counseling*. 31 (1), pp.29–37.

- Szczepura, A. (2005) 'Access to health care for ethnic minority populations', *Postgraduate Medical Journal*, 81, pp.141–147.
- Tabong, P. and Adongo, P. (2013) 'Infertility and childlessness: a qualitative study of the experiences of infertile couples in Northern Ghana', *BMC Pregnancy and Childbirth*, pp13(72).
- Taylor, C. (1985) 'Self interpreting animals', in *Philosophical Papers: Human agency and language*. Cambridge: Cambridge University Press, pp. 45-76.
- Throsby, K. (2004) "'It's different for men": masculinity and IVF', *Men and Masculinities*, 6(4), pp.330–348.
- Timmins, C. (2002) 'The impact of language barriers on the health care of Latinos in the United States: a review of the literature and guidelines for practice', *Journal of Midwifery and Women's Health*, 47(2), pp.80–96.
- Todorova, I. (2011) 'Explorations with interpretative phenomenological analysis in different socio-cultural contexts', *Health Psychology Review*, 5(1), pp.34–38.
- Todorova, I. and Kotzeva, T. (2006) 'Contextual shifts in Bulgarian women's identity in the face of infertility', *Psychology and Health*, 21(1), pp.123–141.
- Toscano, S. and Montgomery, R. (2009) 'The lived experience of women pregnant (including preconception) post in vitro fertilization through the lens of virtual communities', *Health care for women international*, 30(11), pp.1014–1036.
- Turner, A., Barlow, J. and Ilbery, B. (2002) 'Play hurt, live hurt: living with and managing osteoarthritis from the perspective of ex-professional footballers', *Journal of health psychology*, 7 (3), pp.285–301.
- Ulbrich, P., Coyle, T. and Llabre, M. (1990) 'Involuntary childlessness and marital adjustment: his and hers', *Journal of Sex and Marital Therapy*, 16, pp.147–158.
- Upkong, D. and Orji, E. (2006) 'Mental health of infertile women in Nigeria', *Turk Psikiyatri Dergisi*, 17(4).
- Van Balen F, Inhorn, M. (2002) 'Infertility around the globe, new thinking on childlessness, gender and reproductive technologies' (eds) in *Interpreting infertility a view from the social sciences* Berkeley, Los Angeles, USA: UCLA-press, pp.3–32.

- van Rooij, F., van Balen, F. and Hermanns, J. (2009) 'The experiences of involuntarily childless Turkish immigrants in the Netherlands', *Qualitative Health Research*, 19(5), pp.621–632.
- Vanhaecht, K., Panella, M., van Zelm, R. and Sermeus, W. (2010) 'An overview on the history and concept of care pathways as complex interventions', *International Journal Care Pathway*, 14(3), pp.117–123.
- Veevers, J. (1980) *Childless by choice*. Toronto: Butterworth.
- Vision, G. (2009) 'Fixing perceptual belief', *Philosophical Quarterly*, 59(235) pp.292–314.
- Watt, M. and Liamputtong, P. (2013) 'Sensitive research and vulnerable participants: accessing and conducting research with African Australian teenage mothers in Greater Melbourne, Australia', *International Journal of Nursing and Health Care*, 1(1).
- Waite, L. and Lehrer, E. (2003) 'The Benefits from marriage and religion in the United States: a comparative analysis', *Population and Development Review*, 29(2), pp.255-275.
- Webster, G., Teschke, K. and Janssen, P. (2012) 'Recruiting of healthy first-trimester pregnant women: lessons from the chemicals, health and pregnancy study', *Maternal and Child Health Journal*, 16, pp.430-438.
- White, L., Mcquillan, J., Greil, A. and Johnson, D. (2006) 'Infertility : testing a helpseeking model', *Bureau of Sociological Research*, 62, pp.1031–1041.
- Whiteford, L. and Gonzalez, L. (1995) 'Stigma: the hidden burden of infertility', *Social Science and Medicine*, 40(1), pp.27-36.
- WHO (2010) *Health of Migrants: the Way Forward*. Report of a Global Consultation. Madrid, Spain. [Online] Available at: <http://www.who.int/hac/events/3-5march2010/en/> (Accessed on: 2 November 2016).
- WHO (2004) *Infecundity, Infertility, and Childlessness in Developing Countries*. [Online]. Available at: http://www.who.int/reproductivehealth/publications/infertility/DHS_9/en/ (Accessed on: 27 March 2014).

- Williams, Y (2016) *What is Perception in Psychology? - Definition and Theory - Video & Lesson Transcript / Study.com*. [Online]. Available at: <http://study.com/academy/lesson/what-is-perception-in-psychology-definition-theory-quiz.html> (Accessed: 9 August 2014).
- Willig, C. (2001) *Introducing qualitative research in psychology: adventures in theories*. Buckingham: Open University Press.
- Wilson, C., Alam, R., Latif, S., Knighting, K., Williamson, S. and Beaver, K. (2012) 'Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes: a systematic review', *Health and Social Care in the Community*, 20(1), pp.1–19.
- Woods, P. (2006) 'Qualitative research' [Online]. Available at: <http://www.edu.plymouth.ac.uk/resined/qualitative%20methods%202/qualrs hm.htm> (Accessed on: 5th July 2014).
- Wright, J., Duchesne, C., Sabourin, S., Bissonnette, F., Benoit, J. and Girard, Y. (1991) 'Psychosocial distress and infertility: men and women respond differently', *Fertility and Sterility*, 55(1), pp.100–108.
- Yebei, V. (2000) 'Unmet needs, beliefs and treatment seeking for infertility among migrant Ghanaian women in the Netherlands', *Reproductive Health Matters*, 8(16), pp.134–141.
- Zegers-Hochschild, F., Adamson, G., de Mouzon, J., Ishihara, O., Mansour, R., Nygren, K., Sullivan, E. and Vanderpoel, S. (2009) 'International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) revised glossary of ART terminology', *Fertility and Sterility*, 92(5), pp.1520–1524.

Appendix 1: Topic guide for the involuntarily childless women

1. Introduction

- *Introduce self.*
- *Give background to the research:* I am looking at the perceptions and experiences of involuntarily childlessness among black African women.
- The aim of the research is to explore the experiences of involuntary childlessness. I am talking to people from the black African communities who have difficulty to conceive naturally without success for over a year and are trying to access or have already access infertility services.
- *Brief outline of the interview:* after this introduction, I will like us to talk about your perceptions and actual experience of involuntary childlessness and ways you have tried to resolve it.
- *Explain about the consent procedure, emphasis confidentiality, and audio recording the interview, length of discussion* (approximately 60-90minutes).
- *Explain what will happen to findings from the research:* The information from the research findings will be written up as a thesis for partial fulfilment of study requirement of a post graduate research and published on peer-reviewed journals for wider audience. Research findings will also be presented at seminars and conferences.
- Any questions about the study or interview before we commence?

2. Knowledge of infertility and involuntary childlessness (*Let's talk about your general knowledge about reproduction and fertility*).

- Can you tell me what you know about fertility and infertility? (*Probe for basic knowledge on reproduction*).
- Can you tell me a bit more about what you understand the menstrual cycle to be? (*Probe to know the different stages of the menstrual cycle – the follicular phase, the ovulation phase and the luteal phase – and when it is most possible to conceive during the phases of the menstrual cycle*).
- What do you understand by fertility awareness (*Probe to know their knowledge of the three types of fertility awareness [rhythm, temperature,*

mucus] methods and the method they think is most accurate for conception to occur).

- Have you heard of available treatments for infertility? (*Probe to know where they heard if from – media, friends, family, others and also what type of infertility treatments they know about*).
- What do you know about assisted reproductive treatments (ARTs)? (*Probe for detailed explanation of what they understand by ART and the various types of ART that they know about*).
- Have you sought treatment yet? (*Probe to know what type of treatment – medical or traditional or both*).
- What did you do (in terms of seeking solution) when you discovered that it was taking rather longer to get pregnant? (*Probe for things done in trying to conceive such as taking alternative treatments or fertility diets, seeking help from God*).

3. Experiences of involuntary childlessness (*Now we will be talking about your personal experiences with involuntary childlessness and ways you have tried to resolve it*).

- Can you tell me a bit more about yourself and when you decided to start a family? (*Probe for age at diagnosis and length of marriage, if they have ever conceived before or if their childlessness is as a result of pregnancy loss or child death*)?
- How did you feel emotionally? (*Probe for reasons of feeling ashamed and discriminated*)
- Tell me about your treatment experiences (*Probe to know more about the treatment experience, if there was support from spouse, family and friends or if it was done discreetly*).
- Have you ever used any of the ARTs? (*Probe for experiences with assisted reproductive treatments*).
- Would you disclose or have you told anyone else about the use of ARTs? (*Probe for further explanation; if no, why not; and if yes, how did they react?*).

- How did you feel (emotional reaction) when you discovered there was a problem with conceiving? (*Probe to explore reasons for feelings e.g ashamed, discriminated, social-exclusion etc*)?
- How did you feel when you realised that you will need some help to conceive a pregnancy? (*Probe to know if they were feeling depressed and devastated or happy and hopeful*).
- Tell me about your treatment experiences (*Probe to know more about the treatment experience, if there was support from spouse, family and friends or if it was done discreetly*).
- How did you feel (emotional reaction) when you discovered there was a problem with conceiving pregnancy? (*Probe to explore reasons for feelings e.g ashamed, discriminated, social-exclusion etc*)?

4. Perceptions of involuntary childlessness

- How important is it for you to have children? (*Probe for the importance of motherhood*)
- What have you heard about childlessness before you realised your difficulty in conceiving? (*Probe for perceptions on infertility, treatment options, coping strategies, relationship in the family and community*)?
- Have you ever felt pressured to have children? (*Probe to know whom they felt pressured from – family, friends, place of work, community*).
- Do you sometimes feel stigmatised, excluded or left-out because of this? (*Probe to know if they experience some form of shame or stigma during important family functions such as anniversaries, funerals, weddings, birthdays, baby showers etc.*).
- How do you cope with involuntary childlessness and what are your coping strategies? (*Probe for knowledge on how, if religion family friends or other support groups have helped as part of coping strategy for their condition?*)
- How do you feel when other friends and family announce their pregnancy? (*Explore feelings and reactions such as being upset, jealous, withdrawing from conversation with others*).

- Who/what influence you towards your uptake of the treatment? (*Probe to know if there was pressure to seek and take up infertility treatment from spouse, family and community*).
- Did your thoughts about becoming a parent change after you were diagnosed with fertility problem(s) or when you realised it was difficult conceiving or maintaining a pregnancy? (*Probe to know in what way*).
- What do you think about ARTs? (*Probe to know if ARTs are perceived to be a major breakthrough to solve infertility problems in their community*).
- Has your experience and situation change your views of medical treatments/ARTs? (*Probe for further explanations to know in what ways situation could change views*).
- How far will you pursue your desire to have a child with ART? (*Probe to know if third party reproduction is an option and if it is culturally acceptable*)

5. Community perceptions of ARTs (*Next I will like us to talk about your views and perceptions about involuntary childlessness as held by your community*).

- How do you think ARTs are viewed by the wider community? (*Probe to know if they what the community know about ART*).
- Do you think you have been treated differently because you don't have children? (*Probe to know in what ways they feel they have been treated*).
- Do you think people would treat you differently if they knew you were to use or have used ART? (*Probe to know how family and community will react if they knew*).
- How important is it in your culture to be biologically related to any child conceived? (*Probe for why and how*).
- Would you consider using donor gametes (*Probe to know if their culture accepts the idea and use of donor gamete*).

Recommendation for policy and practice

(*In conclusion, what message would you like to put across regarding involuntary childlessness*)?

- What would have made this journey a bit easy if there are any issues with family, friends, community and the healthcare providers (*Probe for views on what they think would have made them cope better e.g support and encouragement*).
- What suggestion(s) would you like to put across to the community where you come from that could help curb the issue of discrimination, stigmatisation and social-exclusion of involuntary childless people (*Probe for any message they will like to send across to family*)

Closing

(I would like to ask you some final questions to bring the discussion to a close)

- Summary of suggestions and recommendation.

Thank participants for their time and contribution and very importantly, stress confidentiality!

Fill in a short questionnaire.

Appendix 2: Consent Form

1. I confirm that I have read and understood the information sheet dated 2015 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.

☐

3. I agree to take part in the above study.

☐

Name of participant:

Date:

Signature:

Name of person taking consent:

Date:

Signature:

Appendix 3: Demographic questionnaire for the involuntarily childless women

It will be very useful if you could provide the following information. Any answers you give will be in the strictest confidence and all information will remain anonymous.

1. How old are you?

2. What is your country of origin?

3. What is your religion?

Christianity

Islam

Others (please specify)

4. What is your level of education?

Tertiary

Secondary

Primary

5. What is your employment status?

Paid employment

Self-employed

Not working

How long have you been married or been in your relationship?

Appendix 4: Participant information sheet for the involuntarily childless women

This information sheet tells you the purpose of this study and what will happen to you if you take part. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

The Research: This research is exploring the perceptions and experiences of involuntary childlessness among the Black African communities in Luton.

What will happen? I would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. We will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 60-90minutes.

What is the study about? There is little information on the experience of infertility and subsequent treatment with assisted reproductive technologies, and not much is known about the perceptions and experiences of those from Black African communities. This research aims to create a better understanding of how ethnicity influences the perceptions and experience of infertility or involuntary childlessness among those of the black African communities.

Why have I been invited? Women who are from the black African origin who have had some difficulties to either conceive or maintain a pregnancy and reside in Luton are invited to share their personal experiences about their infertility/involuntarily childlessness journey. We will be talking to about 10 individuals who fit into this category.

Do I have to take part? Participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. However, you are still free to withdraw at any time and without giving a reason for your withdrawal.

What will happen if I take part? If you consent to take part in the study, the researcher will contact you to make an appointment to meet and speak with at your convenient time and venue. The researcher would like about 60 - 90minutes of your time, to ask you some questions about your knowledge, perceptions and experiences regarding involuntary childlessness or infertility. The researcher will audio record your interview if this is acceptable, in order to help make accurate record of your conversations and thereby not missing out any valuable information that you give.

What will I have to do? All you will be required to do is agree on a convenient time and venue where you can speak freely about your experiences with the researcher. It will be a one-off interview and you will not have to worry about meeting up again except you have some concerns and would want to meet up again.

What are the possible disadvantages and risks of taking part? The topic of involuntary childlessness or infertility is sad and may make you feel upset. The interviewer will be quite sensitive to this. As much as harm is not anticipated in the course of this study, should there be any form or cause of distress during this interview or afterwards, please feel free to contact the researcher on the details provided on the last paragraph of the last page of this information sheet. But for professional counselling support, please feel free to contact the infertility counselling services which will be handed to by the researcher you after the interview.

Will my participation be kept confidential and what happens to the information? All information you give is entirely confidential. No one will be able to identify you from the study. Therefore your real names will not be used rather pseudonyms or codes will be used for easy collection and analysis of data. All information you give will be audio recorded and will be stored securely on the study designated computer which can only be accessed by the research team through a password. Data collected for this research will be written up as a report for publication and made available for participants who will be interested to know the findings from the study; and also as a thesis will be produced in partial fulfilment for a postgraduate degree. All raw data collected on the audio recorder will be destroyed at the end of the study.

What will happen to the findings from the study? Findings from the study will be produced as a thesis for the fulfilment of a research degree, published on both

national and international academic journals and also presented in conferences. No one will be identified in any publication or report.

Who has reviewed the study? The study has been reviewed and given favourable opinion by the University of Bedfordshire Research Ethics Committee. It is supervised by Dr. Nasreen Ali and Prof. Gurch Randhawa of the University of Bedfordshire.

Contact for further information: Thank you for your interest. If you would like any further information about the study or need to ask any questions please contact ndifreke.atang@beds.ac.uk or telephone 07859999929.

This study is being supervised by Dr. Nasreen Ali, Senior Researcher Fellow in Public Health, University of Bedfordshire. If you have any questions or concerns about this study, you should contact her on 0796906248 or email Nasreen.Ali@beds.ac.uk.

Appendix 5: Recruitment announcement for involuntarily childless women

I am Ndifreke Atang, a research student from the Institute of Health Research conducting a study which explores *infertility or involuntary childlessness* experiences among *Black African communities* living in Luton

Your experiences are important...

I need your help in understanding black African women's perceptions and experiences about infertility and involuntary childlessness.

I would like to hear from;

- Black African women (within 25-49 years of age) based in Luton,
- Are married or in a long term relationship,
- And have no child.

All information shared in this study will be treated in confidence and no participant will be identified.

Contact for further information: If you would like any further information about the study or need to ask any questions please contact ndifreke.atang@beds.ac.uk or telephone 07859999929.

Thank you.

Please contact Ndifreke Atang for more information and to volunteer.

Phone: 07859999929; or Email: ndifreke.atang@beds.ac.uk

Appendix 6: Recruitment poster for the involuntarily childless women



The poster features a background of a medical chart with a line graph and a pink pregnancy test stick. Two small inset images show a baby's feet. The text is centered and reads:

Are you Black African residing in Luton?
Are you a female, aged 25 - 49 years?
Will you like to share your experience on **infertility and involuntary childlessness**?

for more information or to volunteer, contact:

Ndifreke Atang
ndifreke.atang@beds.ac.uk

University of Bedfordshire

Appendix 7: Recruitment Advert for Online Infertility Forum

Hello,

I am a research student from the University Of Bedfordshire Institute for Health Research exploring a sensitive and thoughtful research on the perceptions and experiences of involuntary childlessness among the Black Africans in the UK but using Luton, Bedfordshire as my study location.

I am looking for Black African women who have never had a child and have been trying to conceive for over one year, age 25 – 49 years residing in Luton and are willing to talk about their experience of involuntary childlessness.

Please note that due to the sensitivity of the issue, the entire study will be completely anonymous and interviews will take place at a place and time at your convenience.

Upon completion of the study, the result will be analysed and I will be happy to share some of the findings here when they become available.

Should you have any questions, please feel free to contact me by sending me a message.

Thank you for your help!

Appendix 8: For Help and Support

This study aims to explore how ethnicity influences the perceptions and experiences of involuntary childlessness among Black Africans in the UK.

A significant number of women from the Black and minority ethnic (BME) communities are reported by the Human Fertilisation of Embryology Authority in the UK to be experiencing difficulty in achieving pregnancy or maintaining one.

There has been limited focus on the experiences of involuntary childlessness with the BME despite the potentially large numbers of individuals from the BME communities who are affected. As the social context of infertility is highly significant in shaping individuals experiences, this study aims to understand this better in the context of the black African women living in Luton.

It is hoped that the findings from this research will provide in-depth understanding to the experiences of involuntary childlessness which will in-turn provide feedback learning to the infertility services in Luton.

Thank you

If you have experienced distress and would like to talk to someone, please contact:

- Infertility Network UK
National Helpline – 08000087464
Opens 10:00 – 16:00
admin@infertilitynetworkuk.com
- University of Bedfordshire
The Student Counselling Services - 01582489338
counselling@beds.ac.uk
- Miscarriage Association
National helpline – 01924200799
info@miscarriageassociation.org.uk

Appendix 9: Ethics approval confirmation letter



11 August 2015

Ndifreke Atang
Student number: 1019915

Dear Ndifreke Atang

Re: IHREC Application No: IHREC559

Project Title: Exploring the knowledge, perceptions and experiences of involuntary childlessness among Black Africans in Luton

The Ethics Committee of the Institute for Health Research has considered your application and has decided that the proposed research project should be approved subject to a minor amendment that has now been satisfied.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Suzanne Murphy'.

Dr Suzanne Murphy
Associate Director,
NIHR Research Design Service,
Institute for Health Research,
Member of Institute for Health Research Ethics Committee

Appendix 10: Step 4 clustering of themes (IC participant 4)

Superordinate themes	Sub-themes
Understanding of reproduction/fertility	Knowledge – infertility and fertility Understanding of the menstrual cycle
Knowledge of fertility treatment	Hormonal balance with tablets IVF, IUI Herbs – traditional treatment Concoction to drink – traditional treatment
Investigation and treatment experience	Treatment done Treatment - sperm production And help with ovulation Considering treatment options Eagerness – mother Felt terrible, de-humanised, opening up to every doctor Embarrassed Doctors insensitivity Feeling inhumane Feels more under pressure than the man Very emotional Very long process

Importance of motherhood	<p>Someone to share with</p> <p>Seeing a smaller version of self</p>
Pressure of infertility	<p>Pressure to conceive</p> <p>Pressure from family</p> <p>Pressure from own mother</p> <p>Married a virgin – worried about no pregnancy</p> <p>Constant pressure from mom</p> <p>Pressured to see mother's gynea doctor</p> <p>Pressure – mother</p> <p>Concerned, worried – mother</p> <p>Keeping count on cycle – mother</p> <p>Avoidance – due to pressure</p> <p>Pressure from peers – mother</p> <p>Comparison with others – that had kids</p> <p>Blame and misunderstanding</p> <p>Thinks she is not bothered – mother</p> <p>Tells mother off – pressure and stress</p> <p>Breaks down, self-control, tensed</p> <p>Distress – impact of pressure to conceive</p>
Intruding personal space	<p>Intruding into very private matter – mother</p> <p>Asking very personal questions</p>

Disclosure and exposure	<p>Intrusive question</p> <p>Fear of stigma</p> <p>Fear of being found out</p> <p>Shame of exposure</p> <p>Fear of exposure</p> <p>Cannot be disclosed – IVF</p> <p>Avoid disclosure to family and friends</p>
State of deep unhappiness	<p>Grief and questions self</p> <p>Feeling worthless – negative comparison</p>
Coping strategies	<p>Working on managing self</p> <p>Self-control</p> <p>Focus</p> <p>Building their relationship</p> <p>No pressure from husband</p> <p>Build-up/develop self</p> <p>Spend time out</p> <p>Worry less</p> <p>Go on holidays</p> <p>Meet up with friends</p> <p>Start-up career</p>

Relationship with others	No negative impact
Support from family and friends	Husband – supportive Feeling positive
Managing self with the public	Embarrassed at certain hospital section – trying to hide away Feeling stigmatised Hiding away, avoidance - shame of exposure Taboo situation to be avoided
Frustration, hopelessness and helplessness	Feeling helpless, hopeless and frightened Nothing is guaranteed Fulfil and experience parenthood
Perception of causes of infertility	Late marriage Life style – promiscuity Unknown cause – unexplained infertility Distance – couples living in different states
Social judgment	Making insensitive remarks Insensitive remarks from strangers or casual friends

Others pregnancy news	<p>Heart sinks, panics</p> <p>Expect more pressure from mother</p> <p>Compares with others</p> <p>Conflict of emotions</p>
Coping with of emotions	<p>Grieving and feeling bad</p> <p>Fear of getting old without a child</p> <p>Fear for the future</p>
Trying to conceive	<p>Keep praying, hoping, following doctor's advice</p>
Community perception of ART	<p>Educated people – positive perception</p> <p>Average people – expensive</p> <p>Conflict of outcome – disabled child</p> <p>Should be avoided – spiritual</p> <p>Negative perception of non – natural conception</p> <p>Adopted child equivalent to no child</p> <p>Adopted child – vagabond</p> <p>Prefers adoption to donor</p>

Shame and stigma	<p>Excluded</p> <p>Segregated</p> <p>Fear of disclosure because of stigma</p> <p>Stigmatised</p> <p>IVF stigmatised if disclosed</p> <p>Taboo</p>
Own perception of ART	<p>Donors – unacceptable</p> <p>Prefers adoption to gamete donor</p> <p>Feels not desperate to consider donor</p> <p>Fear of complications in future</p> <p>Fear of exposure</p> <p>Decision of donor depends on husband</p> <p>Family member can be considered a donor</p> <p>May back-fire</p> <p>Used against the woman</p> <p>Child perceived as vagabond</p>
Recommendation	<p>Support</p> <p>Don't pressurise</p> <p>Build-up relationship</p> <p>Encouragement</p> <p>Treatment experiences are difficult – empathise</p> <p>Encourage use of IVF</p> <p>Stop stigmatising against women that use IVF</p> <p>Share experience without being shamed</p>

	<p>Have faith, be positive</p> <p>Look for solution in the right places</p> <p>Create awareness about ART</p> <p>Encourage use of ART</p> <p>Encourage test and diagnostic investigations – men</p> <p>Create awareness of the causes of infertility</p> <p>People should get checked</p> <p>Create special awareness targeting young adults</p> <p>Awareness and sensitisation of infertility, causes and treatment</p> <p>African communities in the UK stop discrimination</p> <p>Stop passing insensitive comments</p> <p>Stop secrecy</p> <p>Having frontiers from same community – helps with confidence and trust</p> <p>Family support is important when going for IVF</p>
--	--

Appendix 11: Example of superordinate themes with quotes

Step 5: Table of super-ordinate themes and themes (IC participant 4)

Super-ordinate Themes	Page/Line	Quote
Understanding of reproduction/fertility	P1 L4 – 6	...it has to do with a woman's reproduction, so when we say a person is infertile that means the person is unable to get pregnant and fertility is when that person is able to get pregnant...I think that's within that context
Knowledge of fertility treatment	P2 L43 – 59	...they've got the one that helps you to produce more eggs, that's the clomid....and then erm, they've got the IVF one....natural IVF one and the one that is artificially inseminated [...]there are traditional ones...herbs, you have to take certain herbs for a certain period of time...
Investigation and treatment experience	P7 L194 – 197	...sometimes I felt embarrassed you know....sometimes the doctors themselves having to see so many patients during the day, they are not quite sensitive like you are another piece of meat, 'let's get this over with' kind of treatment
Importance of motherhood	P10 L307 – 311	...I mean how can I be full of so many good things and there is nobody to share it with [...] there is someone you just want to pass on all you know....just help to see another little person like you and help the person become successful...you know...it is really important for me to see like how does it feel to be a parent ...

Pressure of infertility	P4 L109 – 121	...my mum really was something else...she was...I think she started giving me pressure after a month and a half after I got married [...]. ‘so why are you not pregnant, [...] you should come over, we should begin some tests’....and after a period of time I had to travel to see her doctor and her gynaecologist...
Intruding personal space	P4 L116 – 131	Yeah, ‘what happening?’....erm ‘is your husband....does he know how to make love?’ [...].Yes... ‘are you sure you are cooperating’ [...] then I went back and then she was calling me like week after week.... have you seen your period?’.... ‘yes I saw my period’... [...]. She will start counting for me....so she was more like keeping track
Disclosure and exposure	P8 L245 – 248	...and most times you come, you have to wait and then when you wait at a certain section of the hospital, people know why you are there, and they are looking at you....you know...kind ofalready there is a stigma ‘she doesn’t have a child...she cannot get pregnant’ kind of look..
State of deep unhappiness (explosion of feelings)	P6 L190 – 194	...I think I just felt like ‘why can’t I be like every other woman, even mad people get pregnant without effort’ [...].Yeah....they get pregnant without effort, so why can’t I get pregnant easily without all these ciao and all these scientific things...

Coping with infertility/involuntary childlessness	P11 L332 – 338	My coping strategy was to build up myself that was the first thing, at least to make myself happy because I understood that your emotions could affect your ability to conceiveso you need to be in a right frame of mind at all the time [...]. not edgy and all that you know, so what I will find myself doing was to maybe spend more time out...
Support from family and friends	P7 L210 – 216 ‘if we don’t have babies we are not going to die’, he said...I mean it’s not the end of the world [...]. ‘You know am getting married to you not because....I would love to have children but if we don’t have children...I mean that’s not what our marriage is all about’,...
Managing self with the public	P8 L245 – 251	...and most times you come, you have to wait and then when you wait at a certain section of the hospital, people know why you are there, and they are looking at you [...] already there is a stigma [...] it’s written there, you know...you are sitting in that section...that kind of look, you know, but you just get on with everything...
Frustration, hopelessness and helplessness	P9 L – 263	I felt helpless...I felt frightened....because everything they tell you had a side effect [...] it’s not a guaranteed situation [...] and you are always like ‘will it happen, will it not happen’ ...you know, you are like helpless, you can’t help yourself, you just need those people to just come up with whatever expertise you know can help you [...] it’s really a

		hopeless situation to be really.....
Perception of causes of infertility	P10 L320 – 324	... I heard quite a lot, some people because they didn't marry on time, and erm probably that's why they didn't have children on time...ermm...some people were because of life style...maybe during their young teenage age stories I heard from them, they were unable to conceive, at least to those people there was a reason...
Social judgment	P13 L405 – 408	Churches....yeah....meetings especially meetings where you've got Africans...you can tell a lot by how they treat you....maybe when other people are talking about their children and the challenges they are having with parenting 'you, you don't understand what we are talking don't worry until when you have your child' kind of talk...
Others pregnancy news	P11 L352 – 360	...my heart will sink [...] the reason why my heart will sink is the first reason is my mum [...]. She will just say 'Oh B have you heard....have you heard that this person's daughter has just had a child'you know what, she will say their last born, the that is after the one that is your mate...

Explosion of emotions	P11 L362 – 368	...sometimes I will be happy but you know this ‘oh why can’t it be me’ kind of feelings [...] ‘How I wish kind of’, you know.... ‘what wrong with me kind of feeling’you feel bad and then for a while you are thinking about [...] how many years have you got now.....if I have a child now, when he’s 10 years how old will I be kind of thing...
Community perception of ART	P12 L384 – 390	...well for educated people, is seen as a solution....I mean people who are well exposed [...] but some other people [...] they are not sure if it’s the kind of child you are going to have....some of the people will say the child is not going to be a proper child [...] people who are called imbecile....
Shame and stigma	P13 L400 – 403	...especially when it’s women’s event....and they are taking about children... ‘erm you don’t really understand because you don’t have one’ kind of talk.....erm...or when they are addressing parenting issues, they address...you know you can actually see this segregation...they address some people with children....
Own perception of donor ART	P15 L469 – 489	...it’s something big ...it is something that requires a big decision. [...] Yeah that is a big....you know the problem, it is so complicated in future...I don’t want to put myself, my husband and the child in the situation....

Recommendation	P20 L636 – 640	...families need to encourage people....because when someone tell you it's IVF, they will like 'ahh....why should it be an IVF....why shouldn't you...can't you conceive....why not this'you know....and even if it's 'IVF there should also be a support system from people...
----------------	----------------	---

Appendix 12: Master table of themes

Step 7: Master table of themes for the group of IC participants

Themes/quotes	Page/line
<p>The vulnerable self</p> <p><u><i>Coping with feelings:</i></u></p> <p>Theresa: ...at first am like oh God why me? Why me now? Does it have to be me? [...] cos the last time I even spoke to my lawyer and it was like flood gate of = the tears I was holding back = I just let it flow and then [...]. Then every night I realised that I hardly sleep = I just close my eyes and then I hear myself talking in prayers = I've tried to do fasting but because of ulcer I cant.</p> <p>Alexia: ...I think I just felt like 'why can't I be like every other woman, even mad people get pregnant without effort' [...]. Yeah = they get pregnant without effort, so why can't I get pregnant easily without all these ciao and all these scientific things...</p> <p>Christy: Emotionally...it makes you ask questions....you ask questions definitely = it's even worse when you are told everything is ok = and ermmm = and then you are wondering where next = and maybe IVF like a lot of people would recommend....but it's not a good place to be really and I think such people really need encouragements...</p> <p>Precious: ...one night my husband started behaving as if he is mad.....opened the window and started throwing my loads outside [...]I knelt down in the living room = pulled all my cloths away and became naked and say.... 'I have married you because I love you, I don't create children but because you are sending me away because I have no children, you will not hear the cry of a baby till I come back'...</p>	<p>P10 L245 – 263</p> <p>P6 L190 – 194</p> <p>P7 L222 – 225</p> <p>P2 L53 – 54</p>

<p>Naomi: ...it is an understatement to say that I was....emotional roller coaster...you know...some months I will be hopeful, some months I will be completely...completely overwhelmed and I'll be crying and everything but I had to go on with life.</p>	<p>P6 L143 – 146</p>
<p><u>Body/self-image:</u></p> <p>Theresa: It made me so fat, that's why am still trying to drop down, and the pregnacare.... they all made me to be fat. [...]. Someone says, “ you are fat when you are having a baby....you haven't had a baby and you are this big”....just stupid question...</p> <p>Naomi: ...I don't know if you knew that I had fibroid...obviously that made my stomach bloat so people make comment...people are like...you know my mother in-law before she died...before she passed on...anytime I went to visit, she was just staring at my stomach, and I can read her expression like...</p>	<p>P4 L84 – 136</p> <p>P10 L264 – 267</p>
<p><u>Self in public domain:</u></p> <p>Theresa: ...and every day I walk into the store....2 or 3 days ago, he reminded me = I am giving you morning shifts = cos he said to me, “if I give you evening, how do I expect you to have children, now am giving you morning shifts try and” [...]. he's comparing me with my colleagues....she's 5 years married and she's not trying[...] and he's comparing me with her = sometimes I just feel like saying to him, “shut-up!”</p>	<p>P14 L346 – 358</p>

<p>Alexia: ...and most times you come, you have to wait and then when you wait at a certain section of the hospital, people know why you are there, and they are looking at you [...] already there is a stigma [...] it's written there, you know...you are sitting in that section...that kind of look, you know, but you just get on with everything...</p> <p>Christy: ... the other day, just speaking to a man about something...with the children department [...] immediately I just said children, someone walked up to me saying 'I have a word for you' am like it's not the time [...] cos I don't like this thing of...when you are talking about children, then everyone who is around you knows 'oh am encouraging her. You can encourage me with this privately [...] you don't have to do it like [...] is a problem.</p> <p>Martha: ...what we do when we are outside = people don't even know that I don't have any [...]. I have good friends around; they don't pressure me [...]. I think because it's a very sensitive issue...they don't want talk about it as we = they respect the position that I am in = just err = it's working out for me so far...</p> <p><u>Importance of motherhood:</u></p> <p>Alexia: ...I mean how can I be full of so many good things and there is nobody to share it with [...] there is someone you just want to pass on all you know = just help to see another little person like you and help the person become successful...you know...it is really important for me to see like how does it feel to be a parent ...</p> <p>Martha: ...when I was a child because in Africa = in our community [...] they start mentioning from the age of 12, 'oh when you get married' =</p>	<p>P8 L245 – 251</p> <p>P9 L291 – 299</p> <p>P4 L146 – 161</p> <p>P10 L307 – 311</p> <p>P4 L121 – 127</p>
--	---

<p>'When you have children' = so motherhood is being thrown at us at little age = and the value of children are being thrown at you...</p> <p>Naomi: Well, motherhood is something that is of paramount important me [...]. Because is it every woman who gives birth to children that you can actually call a mother? [...]No, in my own opinion no.</p> <p><u>Helpless:</u></p> <p>Theresa: my manager is like am going to strangle him one day (laughing) = he's like, "when are you going to have a baby? Am like soon = and then someone else have been pushing = you better have a baby that she's now pregnant = and am like = omg = the whole store is pregnant [...] my friend one of my colleague [...] I've been pushing = me when they ask me = am like, "don't worry" = you know how ...</p> <p>Mary: Why would I want this on me...so the person whom I married, even though he was educated [...] I could see where the mentality was going.... So I thought to myself....erhhh....am not waiting for this to get to that [...] if I can't have it and they will keep telling me 'oh try and keep trying [...] and then they are putting pressure on me ...</p> <p>Alexia: I felt helpless = I felt frightened = because everything they tell you had a side effect [...] it's not a guaranteed situation [...] and you are always like 'will it happen, will it not happen' = you know, you are like helpless, you can't help yourself, you just need those people to just come up with whatever expertise you know can help you [...] it's really a hopeless situation to be really....</p> <p>Precious: ...we were separated for one year = then the wife left = I developed insomnia = I couldn't sleep [...]I couldn't function = I get to my lectures, my head of department was calling me to ask 'what is wrong?' = my grades dropped. = I confided in him and said I have separated from my husband...</p>	<p>P6 L221 – 227</p> <p>P14 L339 – 345</p> <p>P5 L136 – 145</p> <p>P9 L293 – 263</p> <p>P3 L71 – 78</p>
--	---

<p>Self and the Social World</p> <p><u>Pressure of infertility:</u></p> <p>Theresa:and then after 2 months = the pressure from my parents was [...] she's like = oh it can't be the pressure she's just worried about my in-laws I guess [...] am sure she's worried because one day my in-laws will ask and my father-in-law = he has so much faith in me = I think that's what she's trying to protect .</p> <p>Mary: ...there was a demand = 'When are you going to have a child?'[...] I would be there and my mother in-law will say, "Oh please marry this one, this one is a teacher, this one is a nurse, this one = that one can have children..." Ahhh = am like seriously? [...]. I can't put up with this = It's either you stay there and be made to feel horrible, miserable for the rest of your life.</p> <p>Alexia: ...my mum really was something else...she was = I think she started giving me pressure after a month and a half after I got married [...]. 'so why are you not pregnant, [...] you should come over, we should begin some tests'....and after a period of time I had to travel to see her doctor and her gynaecologist...</p> <p>Christy:I think I may have worried [...] like a couple of months after marriage = after that apart from external pressure I will tell you I will still be in a right state of mind = but then when external pressure comes, it's like huh [...].because it's really intense when it comes 'oh you are not doing what you should be doing' =so you're wondering what else could I be doing that I haven't done.</p> <p>Precious: I have been living with my husband but the pressure of his people became so much. You know Africa now, soon as you are married they want a child immediately...</p>	<p>P10 L251 – 256</p> <p>P3 L78 – 88</p> <p>P4 L109 – 121</p> <p>P5 L133 – 141</p> <p>P1 L9 – 10</p>
--	--

<p>Naomi: my father in-law on the other hand is one that you know was quite nasty to me = you know yeah so I did feel pressurised. = I did feel pressurised = and that marred my relation with my husband...</p>	<p>P10 L269 – 271</p>
<p><u>'Oh I'm pregnant'- dealing with pregnancy news:</u></p>	
<p>Theresa: My colleague [...] she knows about what am going through because most times I come to work depressed and [...] and then one day she came to work and she's like she's pregnant = no reaction on my face = you know how you are frozen like = I stood = I was holding trays [...]. She was like, " =I have something to tell you" = I just finished telling her now that am going to do a surgery and she's like oh it is well [...] she wanted to leave = then came back = "Am pregnant!" = I just held the tray = I didn't know when I just screamed =Yeah!!!</p>	<p>P18 L465 – 481</p>
<p>Blessing: ...we are all human beings = you feel like, 'God' = 'I want to have my own', 'I want to hear the cry of a baby in my home' [...] Once in a while...you'll just sit down and say, 'God = I just know that this will be over one day, I will surely carry my own babies in my arm' = so it's a natural thing that come once in a while = I don't allow it to weigh me down....</p>	<p>P8 L239 – 245</p>
<p>Alexia: ...my heart will sink [...] the reason why my heart will sink is the first reason is my mum [...]. She will just say 'Oh B have you heard....have you heard that this person's daughter has just had a child' = you know what, she will say their last born, the that is after the one that is your mate...</p>	<p>P11 L352 – 360</p>
<p>Christy: ...maybe because am an analytical person = sometimes you kind of think you just race through your head 'how old are you' ...hmmm = 'ok she had her baby at 36' = hmmm 'ok'...' 'Yes it's possible'= you know, you are playing things in your head...and then when people talk about ermmm = once you are over 35, your chances are slim = are you like = you just keep</p>	<p>P10 L320 – 324</p>

<p>calculating...</p> <p>Martha: Am happy for them = am really happy when I come home I share with my husband. = I am happy for them and if my husband hears it first he shares with me= we are very happy for them = nothing. = I don't feel regret of = or why won't it be = because I know my time will come = I have never really been affected by it at all....</p> <p>Naomi: I have to make a conscious effort to rejoice with them but part of me still feel sad that what is it that = there are times am feeling like 'have I done something wrong?'[...]infact I had to like erm = make a conscious effort to fight my negative emotions, so when I see myself like feeling jealous or feeling down or anything, I do the exact opposite of what am feeling...</p> <p><u>Social judgment:</u></p> <p>Theresa: I stopped going to Facebook because every time I opened Facebook... babies [...] then having to face people asking me stupid questions like, "when are you having a baby?" [...] someone was like, "you never wan born?" I stopped talking to her = I just didn't reply her = there was no point replying her = and when she said it, I was so sad...</p> <p>Alexia: Churches = yeah = meetings especially meetings where you've got Africans...you can tell a lot by how they treat you = maybe when other people are talking about their children and the challenges they are having with parenting 'you, you don't understand what we are talking don't worry until when you have your child' kind of talk...</p>	<p>P5 L181 – 184</p> <p>P12 L326 – 332</p> <p>P4 L94 – 101</p> <p>P13 L405 – 408</p>
---	--

<p>Christy: ... first of all you are trying to help with changing a child who's probably messed up [...] and then it's more like ermmm = 'abeg wait make we do am'...that kind of thing, and then you are in a meeting where there is a talk on parenting, you are not expected to chip in because you have not got any experience ...</p> <p>Naomi: And people were buying stuff = you know, and I came also to pick a few things and she was like 'what do you need them for?' I said ahah = for my own children too when they come = and she was like 'they are not here yet, let those who have children but their thing....</p>	<p>P13 L403 – 406</p> <p>P10 L276 – 278</p>
<p><u>Shame and stigma:</u></p> <p>Mary: ... my mother in-law, I don't know if she was mad or what =because she will meet people and she will say, 'oh this is my daughter in-law, she's been married for this amount of time, and she doesn't have a child [...].That's how she will introduce me = and her husband [...] he would say [...] I was eating food for nothing because I couldn't have children.</p> <p>Alexia: ...especially when it's women's event = and they are taking about children... 'erm you don't really understand because you don't have one' kind of talk = erm...or when they are addressing parenting issues, they address = you know you can actually see this segregation = they address some people with children....</p> <p>Christy: Childlessness, well like in the African setting it's considered a spiritual thing = a spiritual problem = ermmm = childlessness = it's stigmatising [...] especially when the word 'barren' is used [...]. 'It's heavy'= even like when you go to African church you know = so it's just</p>	<p>P11 L331 – 343</p> <p>P13 L400 – 403</p> <p>P8 L254 – 260</p>

<p>one of those things that...it's not a nice word = and I don't accept those...</p> <p>Naomi: ... I wouldn't go to social function [...]you know because people will be having birthdays for their children and stuffs they will invite everyone else but they won't invite me [...]And they like ahh 'sorry now'...even though nobody will answer me, it's obvious I don't have any children to play at the field</p>	<p>P11 L290 – 296</p>
<p><u>Disclosure and exposure:</u></p> <p>Theresa: You know it's easier to tell people that you don't know that you are not so close to...I somehow told my colleague but = she doesn't know the full story = I just gave her like just a little [...]. Like immediately I left the clinic = I called them and they like = this is the plan, "you won't tell you parents-in-law and you would tell your husband and tell who to = and then I told my sister-in-law....</p>	<p>P7 L151 – 159</p>
<p>Blessing: You know, there is nothing wrong in disclosing it you know....the Blacks = they may take it up and say = 'ah, that one = her womb is weak', 'her womb is not strong', [...]. Some they will say = it's not really natural = she's has not really passed through womanhood = I think that's the mentality...</p>	<p>P10 L322 – 328</p>
<p>Alexia: ...and most times you come, you have to wait and then when you wait at a certain section of the hospital, people know why you are there, and they are looking at you = you know = kind of = already there is a stigma</p>	<p>P8 L245 – 248</p>

<p>'she doesn't have a child = she cannot get pregnant' kind of look..</p> <p>Christy: If I had to use it = well because we run a ministry, and I have to encourage someone who is probably considering going for the process = yeah I might have to help that person = build faith and what God can do through medicine ...</p> <p>Precious: Yes I will, some people disclose = some people do disclose that they infuse the sperm together and that they don't look different from others and they can also understand sciences = some kids nowadays know so much than you.</p> <p>Martha: No body, it's just I and my husband really....because it's something I don't discuss with anybody really [...] even people who would have wanted to don't go there during conversation because it's a very sensitive issue....so even if they would love to. They don't go there....the only person that would have done is my mum but she is not here anymore....so, it's just I and my husband.</p> <p>Naomi: ...definitely...the only thing is, I would want it to be like erm...I will have my child, then I will say 'yes, we did IVF', do you get my point...yeah they need to know because people need to change their attitude towards...</p> <p><u>Public perception of childlessness:</u></p> <p>Theresa: ... cos when I said to her I went for HSG, this is the result = she's like, "what church do you go?" = I was angry [...]. The first thing she said to me is, "do you go to a living church?"...I wish she could see my reaction....I was just weak....I now said to her, 'Yes'...'Why?' = "Ehhh...you need to pray o = God forbid = you need to pray"...</p> <p>Alexia: ... I heard quite a lot, some people because they didn't marry on time, and erm probably that's why they didn't have children on time = ermm...some people were because of life style = maybe during their young</p>	<p>P7 L217 – 219</p> <p>P1 L5 – 7</p> <p>P 6 L188 – 192</p> <p>P7 L189 – 191</p> <p>P20 L503 – 510</p>
--	--

<p>teenage age stories I heard from them, they were unable to conceive, at least to those people there was a reason...</p>	P10 L320 – 324
<p>Christy:it depends on the setting = with the Caucasians, they are more = it means it's not an issue with them = but with the African community, it's more like ermmm = it's a big thing = sometime they even doubt your ability to care for a child who is even in your care....</p>	P12 L391 – 394
<p>Precious: ...you know people think if you don't have children in Africa, you are a condemned woman....you are good for nothing [...] they will say 'where is this one coming from? She has gone and educated herself, when she was educating herself, she has aborted all her pregnancy'.....did you follow me?</p>	P3 L90 – 92
<p>Naomi: ...there was one other woman who had come in and she was giving this generalisation like...you know, all of us have done various things when we were young...and am thinking...I didn't do anything with my womb...I didn't even sleep around...my husband is my first sexual partner...</p>	P8 L200 – 203
<p><u>Perception of ART:</u></p>	
<p>Blessing: ... it is 50-50 = no it's less than 50 [...] sometimes it doesn't work...it doesn't really work = it works for some but not for all = so I think it's a technology that is coming in now and erhhh.= it's welcomed but not 100% welcomed = people still want to have their own...as in conceive on their own...</p>	P15 L498 – 503
<p>Alexia: ...it's something big = it is something that requires a big decision. [...] Yeah that is a big = you know the problem; it is so complicated in future</p>	P15 L469 – 489

<p>= I don't want to put myself, my husband and the child in the situation....</p> <p>Christy: ...surprisingly I've heard some Africans who are very ok with it = some are not and ermmm = and some tie it to spiritual things = yeah = I think I know a good percentage who are fine with it = I think it's God working through medicine = and some people just frown at it = and I know sometimes the people make it looks like it contradicts God's ability.....</p> <p>Martha: it's common, I think they are beginning to accept it in a way [...] so I think they need to see the joy in people because it's an old time as well it's something they have been hearing about = well I think they are embracing it now = and this globalisation thing is educating people, people are watching TV = it is the same TV they watch back home as well [...] people are getting more enlightened...</p> <p>Naomi: ...yeah definitely it's welcomed = even have gone to realise that even for ART it still takes the grace of God for it to succeed [...] You still need to have some measure of faith for it to happen ...</p> <p>Coping with infertility/involuntary childlessness:</p> <p><u><i>Trying to stay 'sane':</i></u></p>	<p>P12 L375 – 379</p> <p>P6 L221 – 227</p> <p>P14 L358 – 362</p>
--	--

<p>Theresa: Maybe God has his plan = like maybe = I'll just have twins and that's it [...]. Yeah = so every night I just keep praying = talking to myself = I think now am able to stay sane = I just keep touching (referring to her tommy) = Praying in Jesus name = and my hubby is not worried = It doesn't bother him...</p>	P12 L309 – 317
<p>Blessing: Yeah = most of my baby things are in the house = I couldn't bring them here = we were instructed not to give it out = sorry this is a bit religious = I only brought some as point of contact [...] personally = naturally that's what I do [...] because I am sowing a seed into the child [...] because that is a new born [...] they don't talk but as you bless them = you know = somehow they are speaking but you may not know...</p>	P8 L247 – 259
<p>Alexia: My coping strategy was to build up myself that was the first thing, at least to make myself happy because I understood that your emotions could affect your ability to conceive = so you need to be in a right frame of mind at all the time [...] not edgy and all that you know, so what I will find myself doing was to maybe spend more time out...</p>	P11 L332 – 338
<p>Christy: Am a Christian, and the backbone of whatever I do is usually running to God, you could get into the place of prayer, cry = talk to God about it = so in the place of prayer, He reassures you, I mean that's the way I've learnt to deal with things = I go to God in prayers, He assures you, get a word, then you can carry on again.....</p>	P7 L228 – 231
<p>Martha: Am a Christian like I said [...] as a Christian if what you believe that what you are praying for will come to you = you won't err = you will just keep that faith = and because I believe in God I believe that God will answer my prayer = I didn't need to feel bad about it = that why is it taking so long = we just feel in the right time, it will come....</p>	P3 L99 – 104

<p>Naomi: I was a teacher, I took classes so I had to go on with my life so what I did was to put myself into lots and lots of activities you know...to try and take my mind off from what is going on....</p>	P6 L142 – 148
<p><u>Support and encouragement:</u></p>	
<p>Theresa: I told them and they were like...I should take my time [...]. Was like, “just take your time, don’t let someone disturb you” = Infact, their dad was like, “any news let us know” = they are just cool = yeah...</p>	P7 L163 – 167
<p>Mary: My family have never put pressure on me = never = am not the only one = so it’s no pressure.</p>	P13 L413 – 417
<p>Blessing: Hmm....for some people it is like hell = I think God has been = I must give God thanks in my own case = I’ve never had any form of stigmatisation whether from my siblings or from my in-law = nobody has that time [...]. Even my sister-in-law [...] they desire us to have...but no one is coming to say = ‘ha, how many years now? What is happening?’ No = no = no = I have a good flow with them.</p>	P12 L368 – 374
<p>Alexia: ‘if we don’t have babies we are not going to die’, he said...I mean it’s not the end of the world [...]. ‘You know am getting married to you not because = I wouldn’t love to have children but if we don’t have children = I mean that’s not what our marriage is all about’...</p>	P7 L210 – 216
<p>Martha: My real succour is my husband really [...] my husband hasn’t even gone there at all = you know...he’s not even bothered = you know = he’s getting on with life as life comes everyday = we are just living our lives really...</p>	P5 L164 – 171

Naomi: My husband was not like the usual...you know, like the typical African men that you see around that once their wife cannot conceive or whatever, they just go off...

P6 L148 – 150

Appendix 13: Infertility care pathway

